

2003 SEATTLE-KING COUNTY HIV/AIDS CARE SERVICES COMPREHENSIVE NEEDS ASSESSMENT



**Needs Assessment conducted and report prepared by:
Jeff Natter, MPH, HIV/AIDS Care Services Coordinator
Public Health – Seattle & King County
HIV/AIDS Program**

**Epidemiologic Profiles prepared by:
HIV/AIDS Epidemiology Program Staff**

**Report edited by:
Theresa Fiaño, HIV/AIDS Care Services Program Manager
Public Health – Seattle & King County
HIV/AIDS Program**

**Cover art by:
Craig Labenz**

**Cover design by:
Junelle Schrum**

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Public Health – Seattle & King County

**Alonzo Plough, Ph.D., MPH, Director, Public Health – Seattle & King County
John Wiesman, MPH, Manager, Prevention Division
Robert W. Wood, MD, Director, HIV/AIDS Control Program**

**HIV/AIDS Program Staff:
Frank Chaffee, Manager, HIV/AIDS Programs**

**Pat Migliore, Research Assistant
Deborah Witmer, Research Assistant
Junelle Schrum, Data Entry**

**Seattle Eligible Metropolitan Area
HIV/AIDS Planning Council**

**Jesse Chipps, Planning Council Coordinator
Aimee Welch, Evaluation Coordinator
Patty Jensen/Junelle Schrum, Administrative Specialists**

2003 Needs Assessment Work Group:

Saul Aguilar	Jed Lin	Sam Soriano
Timm Cameron	Aaliyah Messiah	Kristen Tobias
Roberto Gonzalez	Hugo Ovejero	Quinten Welch
Jim Holm	Irma Pedroza	Irene Woo
Gerrie LaQuey	Pam Ryan	

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I. Summary

A. Background

From March through December of 2003, Public Health - Seattle & King County's HIV/AIDS Program and the HIV/AIDS Planning Council for the Seattle Eligible Metropolitan Area (EMA) conducted a comprehensive needs assessment of HIV/AIDS care services in King County. Quantitative epidemiological data, including current infection and case trends, had already been collected and analyzed by Public Health's HIV/AIDS Epidemiology Program and were used in this comprehensive process.

The 2003 Needs Assessment was a research and planning activity that sought to:

- identify the extent and types of existing and potential care service needs among persons living with HIV/AIDS in King County;
- examine the current service delivery system in the County, particularly the system's ability to ensure that persons living with HIV/AIDS can effectively obtain and maintain access to primary medical care and treatment;
- determine the extent of unmet needs in order to plan appropriate care services;
- analyze and compare two-year trends in service utilization, priorities and gaps, and
- develop quantitative estimates of the number of persons in King County who are HIV positive and aware of their serostatus, but not engaged in primary care.

The main objective of the 2003 Needs Assessment process was to provide data to inform decisions related to the Planning Council's prioritization of care services for the Ryan White CARE Act's Title I funding allocation process. (See Appendix A for a list of Planning Council-approved Ryan White service categories.) Additional goals of the project were to:

- assess the current Continuum of Care in Seattle-King County, with the goal of strengthening the system and working towards greater collaboration among diverse communities and service systems;
- provide legislatively mandated information to the federal Health Resources Services Administration (HRSA) on service needs and system response, and
- provide planning information for agencies, organizations, and health care providers.

Efforts were made to collect information from as wide a spectrum of Persons Living with HIV/AIDS (PLWH) in King County as possible, ranging from individuals who are HIV positive but not yet symptomatic to persons with end-stage illness. Traditionally under-served populations of

PWLH were given particular focus, including women, persons of color, persons with histories of homelessness, mental illness, chemical dependency and/or incarceration, and youth/young adults.

The 2003 needs assessment also included efforts to develop quantitative estimates of the number of PLWH in King County who were not engaged in primary care. In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened a workgroup across Titles I and II, comprised of grantee staff, health planners and epidemiologists from Public Health and the Washington State Department of Health. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

This HIV/AIDS Needs Assessment provides a “snapshot” of community services, priorities, and gaps as identified by consumers and providers in 2003. By nature, needs assessment processes must be ongoing to reflect the changing nature of the service delivery system, treatment advances, funding availability, and epidemic trends. Public Health - Seattle & King County, in conjunction with the Planning Council, is currently planning future needs assessment projects that will augment the findings of this most recent process.

B. Methods

Several strategies were employed to solicit input in the needs assessment process:

- creation and distribution of written surveys to PLWH throughout King County (483 valid surveys returned);
- creation and distribution of written surveys to providers of HIV-related services throughout King County, including medical care, dental care, mental health therapy, substance use treatment, and a wide range of support services (182 valid surveys returned);
- key informant interviews with 34 service providers;
- focus groups conducted with 10 sub-populations of PLWH (66 PLWH participating), and
- mathematical analysis and modeling of data related to HIV case reporting and lab reports on T-cells tests and viral loads, in order to develop estimates of PLWH “not in care.”

Public Health - Seattle & King County (Public Health) has conducted several other needs assessment processes related to HIV/AIDS care services during the past two years. These include:

- The 2002 “Gatekeeper” Project, that involved interviews with agencies and service providers

external to the HIV Continuum of Care to find out if they are serving PLWH and referring them into the Continuum;

- “Care Project 2002,” a consumer interview project focusing on how issues of race/ethnicity, sex, and immigration status effect access to and satisfaction with key services (medical care, case management, housing assistance and housing related services, mental health counseling and substance use treatment);
- The 2001 Comprehensive Needs Assessment, that employed similar data-gathering strategies as the current process to identify consumer- and provider-identified service utilization, service priorities, gaps in services, and barriers to accessing services;
- The 2000 “Not in Care” Interview Project, a focused assessment process conducted by the Planning Council and Public Health, that attempted to interview PLWH who, for whatever reasons, were not accessing primary outpatient medical care for their HIV infection, and
- The 2000 HIV/AIDS Care/Prevention Collaboration Project, that explored (1) whether HIV prevention providers in Seattle-King County appropriately refer their HIV+ clients into care services and (2) whether HIV care service providers discuss sex and drug use risk reduction with clients and/or make appropriate referrals for clients with ongoing risk reduction needs.

For further information on any of these former assessments, please contact Public Health’s HIV/AIDS Program at (206) 296-4649.

C. General Findings from the 2003 Needs Assessment

As in previous assessments, most service providers report that their caseloads are comprised primarily of gay, white men. This is particularly true for private medical providers and staff at most of King County’s AIDS service organizations.

Over the past decade, however, provider survey respondents from across the Continuum of Care report seeing increasing percentages of clients from other populations. The most significant changes include increases in the percentage of clients who are persons of color (29% in 2001; 35% in 2003), clients who live outside of Seattle (23% in 2001; 29% in 2003), clients who are primarily speakers of languages other than English (6% in 2001; 11% in 2003) and clients who are men who have sex with men and are also injection drug users (MSM/IDU) (9% in 2001; 13% in 2003).

The percentage of clients among other populations seems to have remained relatively constant or slightly, but not significantly, decreased. This includes the percentage of clients reported by providers who are women (18% in 2001; 15% in 2003), heterosexual injection drug users (15% in 2001; 13% in 2003), clients who have been homeless in the past year (15% in 2001; 13% in 2003), and clients who have been incarcerated in the past year (11% in 2001; 10% in 2003).

Although the percentage of clients reported as being dually and/or triply diagnosed (with HIV, mental illness and/or chemical dependency) has remained relatively constant in the past two years, providers noted that the severity of these co-morbidities has increased.

Providers report that the majority of their clients have good access to primary medical care and HIV medications. Although most clients are responding well to the treatments, providers report that they are seeing more clients who are entering care late in their HIV diagnosis and are already ill. Providers also noted increasing trends in the number of clients are not responding as well to their HIV medications as they did several years ago. This translates into increased morbidity and mortality. Although AIDS-related mortality statistics have remained relatively constant since 1998, providers from several of the County's larger programs note that client deaths are up from an average of one or two per month several years ago, to three or four per month in 2003.

Providers also reported increases in the numbers of clients who are presenting with mental illness. Each of the 34 providers interviewed as part of the key informant interview process noted that depression is on the rise among their clients. In many cases, clients who are in need of mental health counseling do not access this service due to cultural norms and/or personal denial and resistance. Providers also reported that more clients with severe mental illness continue to enter the HIV care service system, including increasing numbers of clients with personality disorders and psychoses.

Substance abuse also continues to be a significant concern among King County PLWH. Although the percentage of clients reported with substance abuse issues has remained fairly constant, providers noted that substance use problems have become more severe in the past few years. Of particular note is the increasing frequency of crystal methamphetamine use among female PWLH, a drug that was previously used almost exclusively by MSM.

Providers also noted that they are seeing an increase in the number of clients for whom English is not their primary language. In 1999, providers reported that an average of 3% of their caseloads were primarily Spanish speaking. In 2001, that figure had risen to 5%. By 2003, providers report that an average of 7% of their clients is primarily Spanish speaking. Providers also continue to report seeing increasing numbers of African refugee PLWH, particularly clients from Ethiopia and Eritrea.

In general, consumer survey respondents reported similar utilization rates for most services in the King County Continuum of Care as were reported in 2001. Ninety-four percent of consumers reported current utilization of primary medical care. Seventy-seven percent were currently using case management services, 71% reported using the Washington State AIDS Drug Assistance Program (ADAP) and 67% reported using dental care services. Providers noted an increase in service utilization among several client sub-populations who had previously been less likely to engage in care. These include foreign-born PLWH, non-English speakers, and persons with histories of homelessness and/or incarceration.

D. Service Priorities

Consumers ranked primary medical care as the highest service priority (services they felt were most important to their health), followed by dental care, the AIDS Drug Assistance Program, case management, and housing services. For most service categories, consumer priorities changed little between 2001 and 2003. The most significant increases were noted in the percentage of consumers who prioritized the AIDS Drug Assistance Program (59% of consumers ranking this service as a priority in 2003, versus 40% in 2001) and emergency financial assistance (up from 31% of consumers in 2001 to 48% in 2003). Consumers were also significantly more likely to prioritize case management in 2003 (57% versus 50% in 2001). The only services which consumers were significantly less likely to prioritize in 2003 were client advocacy (down from 35% in 2001 to 22% in 2003), alternative therapies (29% in 2001; 23% in 2003) and home health care (9% in 2001; 5% in 2003).

Several differences emerged in the ways in which consumer sub-populations prioritized services:

- IDU PLWH were significantly more likely than other consumer populations to prioritize case management, food/meal programs, and day/respite care;
- Female PLWH were significantly more likely than males to prioritize psychosocial support, peer or client advocacy and child care;
- African American consumers were significantly more likely to prioritize emergency financial assistance and child care;
- Latino/a PLWH were significantly more likely to prioritize housing assistance and treatment adherence support programs, and
- Consumers with recent or current histories of homelessness were more likely to prioritize housing assistance, emergency financial assistance, and substance abuse services.

Providers ranked case management as the highest service priority for their clients, followed by the AIDS Drug Assistance Program, ambulatory medical care, mental health therapy/counseling, and housing services. Similar to previous years, providers were significantly more likely than consumers to prioritize mental health counseling (67% versus 30%) and substance use treatment (34% versus 7%). This discrepancy was noted by providers during the key informant interview process, many of whom reported increasing severity of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

The most significant increases in provider-identified priorities occurred in the categories of the AIDS Drug Assistance Program (up from 55% of providers who prioritized the service in 2001 to 76% in 2003), health insurance (23% in 2001; 39% in 2003), case management (68% in 2001; 81% in 2003) and adult day health programs (18% in 2001; 31% in 2003). Services that were significantly less likely to have been prioritized by providers in 2003 included substance abuse services (49% in 2001; 34% in 2003), client advocacy (39% in 2001; 24% in 2003), treatment adherence support (27% in 2001; 14% in 2003) and home health care (16% in 2001; 4% in 2003).

E. Service Gaps

Consumers identified lack of access to emergency financial assistance as the number one service gap (services which consumers stated they needed, but could not get). One-third of survey respondents identified this gap. Among the sub-components of this service category, 27% of respondents identified a gap in accessing grocery vouchers and 21% identified a gap in help paying for utilities.

The only other services that were ranked as a gap by more than a 20% of survey respondents were housing assistance/housing related services and psychosocial support. Within the housing category, 21% of consumers identified a gap in rental assistance and 12% reported that they needed but could not get help in finding housing. The largest gap in psychosocial support was in one-on-one peer support (16%), followed by gaps in support groups (8%) and spiritual and religious counseling (8%). Other services that ranked among the top five service gaps for consumers were legal services and alternative therapies.

For most service categories, consumer gaps changed little between 2001 and 2003. The most significant increase was noted in the percentage of consumers who identified gaps in emergency financial assistance (34% of consumers identifying this gap in 2003, versus 24% in 2001). In 2003, consumers were also significantly more likely to identify gaps in legal services (18% versus 11% in 2001), child care (7% versus 1%) and housing assistance and housing related services (24% versus 19%). The sole service category in which consumers were significantly less likely to identify gaps in 2003 was client advocacy (down from 20% of consumers saying they “needed, but could not get” this service in 2001 to 14% in 2003).

Several differences emerged in service gaps identified by consumer sub-populations:

- Female PLWH were significantly more likely than males to identify gaps in transportation and child care;
- African American consumers were also significantly more likely than other populations to identify gaps in transportation and child care;
- Latino/a PLWH were significantly more likely to identify gaps in client advocacy, legal services, mental health services, food/meal programs, child care, and health education/risk reduction programs;
- Consumers with recent or current histories of homelessness were more likely to identify gaps in emergency financial assistance, housing assistance, oral health care, food/meal programs, transportation, and child care;
- Consumers with recent or current histories of incarceration were more likely to identify gaps in legal services and substance abuse services.

The service that providers most frequently identified as lacking for their clients was housing assistance/housing related services, noted as a service gap by 58% of providers. Within this category, 39% of providers noted that a substantial proportion of their clients needed but could not get help finding housing. Thirty-six percent of providers stated their clients could get not help paying rent.

Other services that emerged among the top five provider-identified service gaps included substance abuse services, mental health services, dental care, and emergency financial assistance and psychosocial support. In the category of substance abuse services, providers reported similar gaps in injection drug use counseling/treatment (32%) and counseling/treatment for other drugs and alcohol (30%). Help paying utility bills accounted for the largest gap in the emergency financial assistance category (25% of providers identifying this service as lacking).

F. Unmet Need for Medical Care

As in previous years, outpatient medical care continues to be identified as a gap by a very small number of consumers. Only 2% of survey respondents (9 out of 483) stated that they needed but could not access outpatient medical care. Eight percent of consumers reported that they needed but could not access Washington State's AIDS Drug Assistance Program.

Only 5% of providers noted gaps in access to medical care for their clients. However, 16% of providers stated that a substantial number of their clients needed, but could not get assistance from the Washington State AIDS Prescription Drug Program. This represents a three-fold increase from the 2001 survey, in which only 5% of providers identified this gap for their clients.

In general, consumer focus group participants reported very few problems accessing medical care in King County. Consumers noted that medical care was available to them and their peers when they chose to access it and that the quality of care they received was excellent. The very small number of consumers who were not currently using medical care or taking HAART medications stated that this was by personal choice. Focus group participants did note several key barriers that may impede their peers from accessing medical care, including severe substance abuse, chronic mental illness, cultural norms against seeking medical care unless one is acutely ill, and denial about one's HIV risk.

In early 2003, a workgroup comprised of staff from Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened to develop quantitative estimates of the number of PLWH in King County who were aware of their HIV status but not receiving medical care. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

At its first meeting, the workgroup agreed to adopt the UCSF definition of “in care”: evidence of a CD4 count, viral load test or administration of HAART therapy within the previous twelve-month period. Persons determined to be “not in care” were those for whom no evidence existed of any of these three clinical markers during the prior year.

The group used data from several sources in making its estimates. Primary data for estimating statewide and local HIV prevalence came from the HIV/AIDS Reporting System (HARS). To

determine PLWH who were “not in care,” the group used data from lab reporting records of CD4 and viral load tests. These data are estimated to be over 95% complete. An adjustment was made on all preliminary data to address the fact that laboratory reporting in Washington State excludes CD4 counts above 200 and undetectable viral loads. Data from the Adult Spectrum of Disease (ASD) study demonstrate that 27.6% of patients in 2000 and 2001 had only non-reportable lab results. As a result, data on care patterns was adjusted to account for patients with non-reportable lab results.

Based on these analyses, it is estimated that 76.1% of King County PLWH who are HIV+ and aware of their serostatus are in care and 23.9% of PLWH meet the UCSF definition of being “not in care.” The “not in care” estimate represents 1,409 PLWH (95% confidence interval: low estimate of 1,336; high estimate of 1,484).

Sub-population analyses were conducted based on sex, race/ethnicity and HIV/AIDS status. Analyses revealed no statistically significant differences in “not in care” status based on these demographic indicators. The workgroup intends to devise methods to incorporate analyses based on other demographic characteristics in upcoming “not in care” estimates.

II. Epidemiological Profile of HIV/AIDS in Seattle-King County

NOTE: The following section has been excerpted from an article that appeared in the HIV/AIDS Epidemiology Report – 1st Half '03 (published jointly by Public Health – Seattle & King County and the Washington State Department of Health). For more in-depth information about the epidemiology of HIV/AIDS in King County and Washington State, please refer to these and other publications produced by the aforementioned programs. Information can also be obtained on Public Health's website at www.metrokc.gov/health/apu.

A. King County AIDS Rates Compared with State and National Data

AIDS case data have been collected nationally and locally since 1981 but describe only persons with advanced HIV disease. Reporting of all stages of HIV infection was implemented in Washington in September 1999. The analyses below are for all King County residents reported with HIV or AIDS through December 31, 2002.

The latest published Centers for Disease Control and Prevention AIDS data¹ show that in 2001, the Seattle metropolitan statistical area (MSA) ranked 24th in the cumulative number and 40th in annual rate of reported AIDS cases nationally. This was among 104 metropolitan areas of one-half million population or higher. The Seattle MSA (which includes King, Snohomish and Island counties) AIDS rate during 2000 was 14.3 cases per 100,000 population.

The five highest rates in the country were in New York City (65.9), Miami (53.8), Baltimore (50.0), Jersey City (42.1), and Fort Lauderdale (41.3). In comparison to the Seattle MSA rate of 14.3, the Tacoma MSA had a rate of 9.3, while the Portland MSA rate was 11.2 per 100,000.

The Seattle MSA cases make up a decreasing proportion of total U.S. AIDS cases as the epidemic move from urban to more rural areas. Seattle accounted for 1.01% of the U.S. total at the end of 1992, 0.95% at the end of 1996, and 0.81% at the end of 2001.

King County has the highest rate of HIV/AIDS among all Washington counties. About one-third of the Washington population resides in King County, but almost two-thirds of all AIDS cases resided in King County at the time of their AIDS diagnosis. Within King County the rate is highest in the city of Seattle.

B. Diagnoses of AIDS and Deaths

Between 1982 and December 31, 2002, a total of 6,679 King County residents have been diagnosed and reported with AIDS and 3,821 (57%) have died. Following the pattern seen nationally, AIDS cases peaked in 1993, declined through 1997, and have been stable at about 250 cases each year from 1998 to 2002 (see figure on Page 10). The number of HIV and AIDS deaths peaked from 1993 to 1995 at over 400 deaths per year, but declined to about 100 deaths annually from 1998 through 2002.

The significantly lower death numbers and delays in progression from HIV infection to AIDS beginning about 1995 are primarily due to widespread introduction of antiretroviral treatments. In addition, effective prophylaxis to prevent opportunistic infections (such as *Pneumocystis carinii* pneumonia), better monitoring of HIV progression (such as by assays of HIV viral load), and prevention efforts in reducing HIV transmission rates have contributed to decreased numbers of HIV and AIDS diagnoses.

After steep declines, the AIDS death and case numbers have been level since 1998. There are a variety of reasons that case numbers have leveled:

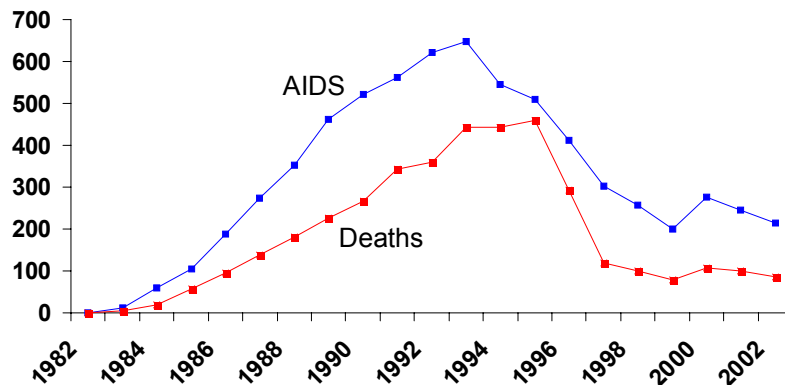
- persons learning their HIV status too late in the course of their HIV disease to receive optimal treatment,
- persons who experience problems accessing treatment, or who may refuse treatment,
- treatment failures due to problems with taking the medicines, adverse side effects, or the development of HIV strains resistant to currently available antiretroviral drugs.

Also, as persons with long-standing HIV infection age, they die more frequently of conditions unrelated to their HIV infection. For example, chronic hepatitis, substance abuse, and mental illness contribute significant morbidity and mortality among this aging population.

New AIDS Cases and Deaths

King County, 1982-2002

Adjusted for delays in reporting



HIV/AIDS was the leading cause of death among 25-44 year old males in King County during the years 1989 to 1996² but dropped to the 6th leading cause of death in 2001.

While both AIDS cases and deaths numbers have decreased, more King County residents than ever are living with AIDS. There are about 250 new AIDS diagnoses each year, relative to about 100 new deaths reported.

C. Number of Persons Infected With HIV

Because effective treatments have dramatically slowed progression of HIV disease and reduced the numbers of deaths, AIDS numbers no longer accurately portray natural changes in the epidemic. To assess the ongoing changes in the overall epidemic we analyzed all reports of HIV infection and AIDS. Public health departments in Washington began collecting case reports of HIV infection in September 1999.

As of December 2001, the Washington State Department of Health estimated that as many as 13,000 Washington residents are infected with HIV, including persons with AIDS³. Since 64.4% of reported HIV and AIDS cases statewide are residents of King County, we estimate 8,400 King County residents currently living with HIV infection or AIDS.

The 8,400 HIV-infected King County residents include about 3,000 persons living with AIDS and 5,400 persons living with HIV but not AIDS. These include 2,852 AIDS cases and 2,111 HIV cases reported to Public Health, an estimated 1,200 HIV diagnoses not yet reported (because reporting is relatively new), and perhaps 2,100 persons who are unaware of their infection status. CDC estimates that one-quarter to one-third of all HIV infected persons in the U.S. are undiagnosed and unaware of their status⁴. An additional 3,821 persons diagnosed with HIV or AIDS in King County have died over the past two decades.

D. Trends in Diagnosis of HIV Infection

Public Health conducted analysis of trends based upon the year of initial diagnosis with HIV infection, whether that diagnosis occurred soon after infection, or at the time AIDS symptoms developed (Table 1). Although HIV reporting data are still incomplete, the number of new diagnoses appears roughly level at 400-500 new diagnoses each year since 1998.

Based upon data reported through December 2002, the characteristics of persons first diagnosed with HIV infection during 1994-1996 were compared to those diagnosed from 1997-1999, and those from 2000-2002. A chi-square test for trend was used to determine if the change in proportions for each group was statistically significant over these three time periods. The statistically significant changes shown in Table 1 may demonstrate shifts in the epidemic, artifacts from implementing surveillance for HIV infection in 1999, or longer delays in getting tested among some population groups.

Although the relative ranking of each group has not changed over time, there have been substantial shifts in the proportion of persons newly diagnosed with HIV infection among different sub-groups. Between the three year periods of 1994-96 and 2000-2002, the proportion of cases increased for heterosexual transmission (from 5% to 12%), females (from 8% to 12%), African Americans (from 14% to 22%), and residents of communities south or west of Seattle (from 8% to 11%). The proportion of cases decreased among men who have sex with men (from 72% to 62%), males (from 92% to 88%), whites (from 73% to 62%), and American Indians (from 3% to 1%).

**Table 1. Demographic characteristics and year of HIV diagnosis for 8,936
Seattle/King County residents reported to
Public Health -- Seattle & King County through 12/31/2002***

	1982-1987		1988-1990		1991-1993		1994-1996		1997-1999		2000-2002		Trend** 1994- 2002
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
TOTAL	1615	100	2028	100	1885	100	1361	100	1004	100	1043	100	
HIV Exposure Category													
Men who have sex w/men (MSM)	1261	78	1597	79	1387	74	977	72	681	68	642	62	Down
Injection drug user (IDU)	70	4	102	5	130	7	94	7	61	6	77	7	Level
MSM-IDU	204	13	221	11	197	10	107	8	79	8	76	7	Level
Blood product exposure	34	2	31	2	17	<1	7	<1	5	<1	7	<1	Level
Heterosexual contact	23	1	43	2	92	5	64	5	69	7	129	12	Up
Perinatal exposure	5	<1	3	<1	8	<1	7	<1	3	<1	2	<1	Level
<i>SUBTOTAL-known risk</i>	<i>1597</i>		<i>1997</i>		<i>1831</i>		<i>1256</i>		<i>898</i>		<i>933</i>		
Undetermined/other	18	1	31	2	54	3	105	8	106	11	110	11	
Sex & Race/Ethnicity													
Male	1569	97	1940	96	1763	94	1249	92	896	89	914	88	Down
White Male	1387	86	1637	81	1429	76	947	70	630	63	607	58	Down
Black Male	87	5	168	8	175	9	154	11	123	12	171	16	Up
Hispanic Male	59	4	81	4	107	6	96	7	103	10	95	9	Up
Asian / PI Male	20		32		37		25	2	25	2	29	3	Level
Am Indian Male	16		22		15		26	2	13	1	8	1	Level
Unknown race Male	0	0	0	0	0	0	1	<1	2	<1	4	<1	
Female	46	3	88	4	122	6	112	8	108	11	129	12	Up
White Female	32	2	52	3	67	4	47	3	43	4	44	4	Level
Black Female	12	<1	25	1	36	2	42	3	52	5	63	6	Up
Hispanic Female	1	<1	2	<1	9	<1	11	<1	5	<1	15	1	Level
Asian / PI Female	0	0	4	<1	3	<1	4	<1	3	<1	2	<1	Level
Am Indian Female	1	<1	5	<1	7	<1	8	<1	3	<1	4	<1	Level
Unknown Race Female	0	0	0	0	0	0	0	0	2	<1	1	<1	

Table 1 (continued)

	1982-1987		1988-1990		1991-1993		1994-1996		1997-1999		2000-2002		Trend** 1994-2002
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
TOTAL	1615	100	2028	100	1885	100	1361	100	1004	100	1043	100	
Race/Ethnicity													
White, not Hispanic	1419	88	1689	83	1496	79	994	73	673	67	651	62	Down
Black, not Hispanic	99	6	193	10	211	11	196	14	175	17	234	22	Up
Hispanic	60	4	83	4	116	6	107	8	108	11	110	11	Up
Asian / Pacific Islander	20	1	36	2	40	2	29	2	28	3	31	3	Level
American Indian / Alaska Native	17	1	27	1	22	1	34	3	16	2	12	1	Down
Unknown	0	0	0	0	0	0	1	<1	4	<1	5	<1	
Age at diagnosis of HIV													
0-19 years	38	2	34	2	25	1	21	2	19	2	13	1	Level
20-29	569	35	539	27	489	26	311	23	234	23	219	21	Level
30-39	682	42	932	46	835	44	605	44	472	47	492	47	Level
40-49	248	15	384	19	407	22	313	23	212	21	244	23	Level
50-59	65	4	102	5	110	6	95	7	55	5	63	6	Level
60+	13	1	37	2	19	1	16	1	12	1	12	1	Level
King County Residence													
City of Seattle	1405	87	1818	90	1611	85	1156	85	854	85	867	83	Level
North and East King County	100	6	100	5	135	7	96	7	61	6	58	6	Level
South and West King County	110	7	110	5	139	7	109	8	89	9	118	11	Up

*Includes persons who later developed AIDS

**Indicates a statistically significant ($p < .05$) trend in the proportion of cases by 3-year interval between 1994 and 2002

These shifts may be related in that much of the heterosexual transmission increase seen is among African American females from south and west of Seattle, while most of the decrease is among white MSM residing in Seattle. The proportion of cases increased among black females (from 3% to 6%), black males (from 11% to 16%), and Hispanic males (from 7% to 9%), and decreased among white males (from 70% to 58% of the total).

E. Persons Living with HIV or AIDS, by Gender, Race / Ethnicity, and Exposure Category

The trends described in the section above must be placed in the context of overall group rankings. Ninety-one percent of persons living with HIV or AIDS in King County are male and 9% are female. Seventy-three percent are White, 15% are Black, 8% Hispanic, 2% Asian or Pacific Islander (API), and 2% Native American or Alaskan Native (NA/AN). (Table 2)

Six percent of cases have no identified behavioral exposure to HIV (using the standard CDC-defined categories). Among cases with known exposure, 70% are men who have sex with men (MSM), 7% are MSM who also inject drugs (MSM-IDU), 9% are injection drug users (IDU),

6% report having a heterosexual partner with HIV or at risk of HIV infection, 1% were born to HIV-infected mothers, and 1% report receipt of blood products (mostly prior to 1985 in the US, or more recently in other countries where effective blood screening has not been implemented).

The distribution of exposure categories differs by race and gender. MSM exposure is most common among all males, accounting for 85% of known exposures among White men, 60% among Black men, 78% among Hispanic men, 85% among API men, and 51% among NA/AN men. MSM-IDU is the second most common exposure among White men (11%), API men (5%), and NA/AN men (33%). IDU is second among Black men (15%), and Hispanic men (11%).

Heterosexual transmission is the most common exposure among almost all women, including Whites (59%), Blacks (62%), Hispanics (81%), and API (71%). Among the relatively few NA/AN female cases, IDU is the most common risk behavior (78%), while 22% had heterosexual partners at risk.

While most diagnoses were among white males, the infection rates per 100,000 population show a higher burden of impact on several groups. The rate among males (537.7) is about ten times higher than among females (53.5). Compared with Whites (285.1), the rates are 2 and one half times higher among Blacks (731.9), and 1 and one half times higher among NA/AN (485.2) or Hispanics (432.6); but much lower among API (51.4). Overall rates are highest among Black and Hispanic males, and lowest among API, White, and Hispanic females.

Table 2. King County residents living with HIV or AIDS and reported to Public Health -- Seattle & King County as of 12/31/2002

	Number		Estimated Infected	2000* Population	Estimated Rate per 100000
	Reported	Percent			
TOTAL	5,115	100	8,400	1,737,034	294.5
RACE/ETHNICITY					
White, not Hispanic	3,732	73	6,150	1,309,120	285.1
Black, not Hispanic	770	15	1,240	105,205	731.9
Hispanic	412	8	690	95,242	432.6
Asian or Pacific Islander	108	2	180	210,156	51.4
Native American or Alaskan Native	84	2	140	17,311	485.2
Unknown	9	<1	N.A.		
SEX & RACE/ETHNICITY					
Male	4,648	91	7,630	864,457	537.7
White Male	3,538	69	5,810	649,271	544.9
Black Male	571	11	940	53,895	1059.5
Hispanic Male	376	7	620	51,662	727.8
Asian or Pacific Islander Male	95	2	150	101,045	94.0
Native American or Alaskan Native Male	62	1	100	8,584	722.3
Unknown Race Male	6	<1	<20	Not applicable	Not applicable

Table 2 (continued)

	Number		Estimated Infected	2000* Population	Estimated Rate per 100000
Female	467	9	770	872,577	53.5
White Female	194	4	320	659,849	29.4
Black Female	199	4	330	51,310	387.8
Hispanic Female	36	<1	60	43,580	82.6
Asian or Pacific Islander Female	13	<1	<20	109,111	11.9
Native American or Alaskan Native Female	22	<1	<20	8,727	252.1
Unknown Race Female	3	<1	<20	Not applicable	Not applicable
HIV EXPOSURE CATEGORY					
Men who have sex w/men (MSM)	3,584	70	6,310	30- 50,000	12,620-21,033
Injection drug user (IDU)	344	7	620	15,000	4133
MSM-IDU	465	9	800	2,500- 3,800	21,052-32,000
Blood product exposure	40	1	70	Unknown	Not applicable
Heterosexual contact	331	6	560	1,245,000	45
Perinatal exposure	21	<1	40	Unknown	Not applicable
SUBTOTAL- known risk	4,785	94	8,400	Not applicable	Not applicable
Undetermined/ other	330	6	N.A.	Not applicable	Not applicable
AGE AT HIV DIAGNOSIS					
0-19 years	126	2	210	434,736	29.0
20-24 years	503	10	830	116,597	431.4
25-29 years	1,022	20	1,680	141,795	720.8
30-39 years	2,255	44	3,680	308,187	731.7
40-49 years	943	19	1,560	292,470	322.4
50 years and over	266	5	440	443,249	60.0
RESIDENCE AT DIAGNOSIS					
City of Seattle	4,388	86	7,230	563,374	778.9
North or East of Seattle	300	6	500	575,548	52.1
South or West of Seattle	427	8	670	597,999	71.4

* 2000 Census Population as of April 1, 2000, with single race bridged estimates

F. Persons Living with HIV or AIDS, by Residence

Eighty-six percent of persons living with HIV or AIDS in King County resided in the City of Seattle at the time of their diagnosis. In contrast, Seattle is home to about 32% of the King County population. Overall, about 8% of persons with HIV/AIDS lived south or west of Seattle, and the remaining 6% resided north or east of Seattle. (Table 2)

There are a number of statistical differences (based on chi-square tests) between the HIV-infected populations inside Seattle compared with outside the city. Residents of Seattle are more likely to be male, MSM or MSM-IDU, White males, or American Indian males. Residents

outside Seattle are more likely to be female (Black, White or Hispanic) and report IDU or heterosexual exposure.

G. Age at Diagnosis

Based upon the age at initial diagnosis of HIV infection, the largest numbers of King County residents reported with HIV were age 25-29 (20%), age 30-34 (24%), or age 35-39 (20%). Only 2% of persons were under age 20. This distribution has remained largely unchanged throughout the epidemic.

The age distribution is different among males and females. Females tend to be much younger than males when first diagnosed with HIV. This is probably because most women are heterosexually infected and may tend to be younger than their male partners.

H. Conclusions

There are an estimated 8,400 HIV-infected King County residents. These include 3,000 persons with AIDS and 5,400 persons with HIV who have not yet developed AIDS. Another 3,800 persons have died since 1982. The numbers of deaths and new AIDS diagnoses have declined substantially in recent years primarily due to effective treatments. Since 1998, the numbers of new cases and deaths appear to have leveled, with about 100 deaths and about 250 new AIDS cases reported each year.

About 400-500 new HIV infections have been diagnosed each year since HIV reporting was implemented in Washington State in 1999. However it is important to note that many persons with HIV infection learn about their infection late in the course of their disease because they had not been tested until they developed symptoms of AIDS.

The total number of persons living with AIDS or with HIV infection in King County is increasing because each year there are more new diagnoses than deaths. Most HIV-infected King County residents currently are White men who have sex with men, are 30-45 years of age, and reside in Seattle. However, based upon the date of initial diagnosis with HIV infection, an increasing proportion of cases are Black males or Black females, and the proportion of cases due to heterosexual transmission is also increasing.

Contributed by Amy Bauer MPH, Jim Kent MS, and Sharon G. Hopkins DVM, MPH

Footnotes

1. CDC. HIV/AIDS Surveillance Report, Volume 13(2), Cases reported through December 2001. Available at <http://www.cdc.gov/hiv/stats/hasrlink.htm>
2. King County Registrar / VISTA
3. HIV Prevalence Estimation in Washington (working document)
4. Sweeney PA, Fleming PL, Karon JM, et al. A minimum estimate of the number of living HIV infected persons confidentiality tested in the United States [Abstract I-16]. In: Program and Abstracts of the Interscience Conference on Antimicrobial Agents and Chemotherapy.

Toronto, Canada: American Society for Microbiology, September 1997.

III. Methods

The needs assessment process used several strategies to gather input from persons living with HIV/AIDS (PLWH) in King County and providers of services to this population. The centerpiece of the process was the creation and distribution of written surveys to PLWH throughout King County. Other components of the needs assessment process included a written service provider survey, focus groups of targeted consumer sub-populations and key informant interviews with service providers.

A. Consumer Surveys

The 2003 consumer survey targeted persons living with HIV/AIDS throughout King County. (See Appendix B for a copy of the consumer survey instrument.) The HIV/AIDS Planning Council's Needs Assessment Work Group oversaw the development of the survey instrument, and staff from Public Health – Seattle & King County were responsible for survey distribution, collection and analysis.

The Planning Council sought to collect information on a wide spectrum of PLWH in King County, ranging from individuals who were HIV positive but not yet symptomatic to persons with end-stage illness. The process emphasized traditionally under-served populations, including PLWH with histories of homelessness, mental illness, chemical dependency and/or incarceration, women, youth/young adults, persons of color and persons living in South and East King County. Survey forms were created in both English and Spanish language versions.

The survey inquired about 32 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they used, did not need/want, or needed but could not get. For each service that consumers used, the survey asked, "If you use this service, how well does it meet your needs?" Consumers were asked to use a Likert scale ranging from "1" (not at all) to "5" (completely) to describe how well each service meet their specific needs. The survey also asked consumers to choose up to seven of the 32 services that they would consider most important in helping them cope with their HIV/AIDS-related health issues. Answers to these questions were used to define consumer "service priorities."

The survey also contained a new section on case management services. This section focused on consumers' experiences in using case management in King County. The survey provided a list of possible reasons why a consumer might not currently have a case manager (or may never have had one), and asked respondents to check all applicable answers. For consumers who used case management during the past year, the survey included a list of services commonly associated with case management and asked consumers if the case manager helped them access the service, was not able to help them access the service or if the service was not needed.

The final component of the survey was an extensive demographic section. This section included questions relating to general demographics (e.g., sex, age, race/ethnicity, area of residence within King County, etc.), as well as questions relating to the individuals HIV-related health status, mental health, substance use, incarceration history, homelessness and risk reduction needs.

In creating the survey instrument, the Planning Council made extensive efforts to safeguard the anonymity of survey respondents. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on return surveys. To further safeguard respondents' confidentiality, the surveys were pre-addressed to the "Planning Council," rather than the "HIV/AIDS Planning Council" or "Public Health – Seattle & King County." Survey forms were bar coded for pre-paid reply.

To reach as broad a range of consumers as possible, survey distribution sites included 48 service agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed at the offices of 27 private medical care providers and 8 private dentists. Public Health delivered a total of 2,584 surveys to various agency and provider sites. Based on data from previous years, it is estimated that approximately 60% of surveys distributed to agencies/providers were actually distributed to consumers. The Planning Council received a total of 483 valid responses, for a return rate of between 19% and 31%.

B. Provider Surveys

The Planning Council created and distributed a provider survey as the second component of the 2003 assessment process. The Council believes that service provider data offers important comparisons to consumer-identified service priorities and gaps, as well as helping to gather input about sub-populations that may not have been effectively represented among consumer survey respondents. (See Appendix C for a copy of the provider survey instrument.)

The survey collected information from as broad a range as possible of providers of service to PLWH in King County. These included primary care providers, case managers, providers of non-Western therapies, private dentists, substance use and mental health treatment professionals and staff from social service agencies. Public Health distributed provider surveys at 59 agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed to 28 private doctors and 8 private dentists.

The survey inquired about the type of service offered by the provider, the total number of PLWH on the provider's current caseload, and demographics of the provider's HIV/AIDS clientele. Using the same list of 32 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important in helping their clients cope with HIV/AIDS-related health issues ("service priorities"). The survey also asked providers to check each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing ("service gaps"). Public Health delivered a total of 432 surveys to various provider sites. The Planning Council received a total of 182 valid responses, for a return rate of 42%.

C. Consumer Focus Groups

The needs assessment process included plans for twelve focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in King County. For the 2003 process, Public Health partnered with AIDS Housing of Washington (AHW) in facilitating the focus groups. During the first hour of each group, Public Health staff focused on medical care and social service issues, while AHW staff asked questions related to housing during the second hour. To better focus on the current medical care system, Public Health attempted to recruit participants who had received medical care in King County for the first time within the past five years. (NOTE: Information gathered on housing issues will be reported in the Seattle-King County HIV Housing Needs Assessment and Plan, created by AIDS Housing of Washington, and due for publication in September 2004.)

The focus group process acknowledges that specific sub-populations of PLWH may present unique utilization patterns, access barriers and service gaps, and addresses the concern that written surveys might not be as well suited to capture information from members of several of the sub-populations. A total of 66 PLWH attended the ten focus groups.

The questions posed to participants focused on:

- current utilization of medical care and associated clinical services;
- reasons, if applicable, for not currently receiving medical care;
- consumers' initial experience in accessing medical care in King County;
- problems encountered in getting medical care and other clinical services;
- the extent of medical care utilization and access problems among their peers, and
- suggestions for improving access to care in King County.

(See Appendix D for a copy of the focus group script.)

Focus groups were held with the following sub-populations of PLWH:

African Americans	MSM of color
Homeless persons (current or in past year)	Native Americans
Incarcerated (current or in past year)	White MSM
Injection drug users	Women
Latinos (conducted in Spanish)	Youth and young adults

Public Health planned two additional focus groups with Asian/Pacific Islander PLWH and men who have sex with men and were also injection drug users (MSM/IDU). Despite targeted outreach efforts and repeated attempts to re-schedule these groups, each was cancelled due to lack of participation. As a result, information regarding service utilization and needs of A/PI PLWH and MSM/IDU are limited in this report to quantitative data from consumer surveys and key informant interviews of service providers to this population.

Service providers across the Continuum of Care disseminated information about the focus groups within the targeted communities and helped to identify potential participants. Participants registered for the groups by calling a central registration hotline, with outgoing messages in both English and Spanish. Participants received \$30 for their time, as well as reimbursement for transportation and/or child care expenses incurred. Food was provided at all groups. Staff recorded each of the groups on audiotape. In addition, a non-participant observer took written notes at each group to assist in the final transcription.

D. Provider Interviews

In order to capture qualitative information about caseload demographics and service trends, staff from Public Health – Seattle & King County interviewed 34 HIV/AIDS care service providers in King County. The providers supplied general demographic information about their client population, including information about HIV-related medical trends and other co-morbidities (mental illness, substance use, etc.).

The interviews also asked providers to comment on:

- trends and changes in the kinds of services their clients are using;
- issues related to enrolling and maintaining HIV+ clients in primary medical care and related clinical services;
- problems related to access to medical care, and
- suggestions on how to overcome access barriers.

(See Appendix E for a copy of the provider interview form.)

As with the focus groups, providers were identified based on their affiliations with specific sub-populations of PLWH. The interview roster included medical providers with large HIV/AIDS caseloads (representing private, clinic and hospital-based practices throughout King County), case managers, mental health providers, substance use treatment facility staff, and jail health staff. Public Health staff also interviewed service providers at several King County community-based organizations (including organizations targeting women, persons of color, youth/young adults, and homeless persons). Each interview lasted between forty-five and ninety minutes. Although most interviews were conducted with individual providers, some providers were interviewed in pairs.

IV. General Findings from the Consumer and Provider Surveys

A. Distribution and Response

Consumer Surveys: Public Health delivered a total of 2,584 surveys (including 274 Spanish language surveys) to various sites throughout King County. Distribution sites included 48 service agencies, and the offices of 27 private medical care providers and 8 private dentists. The Planning Council received a total of 483 valid responses, for a return rate of 18.7% of surveys distributed to agencies. The return rate for Spanish language surveys (34/274; 12.4%) was substantially lower than for English language surveys (449/2,310; 19.4%).

Data from previous years suggests that approximately 60% of surveys distributed to agencies and providers were actually distributed to consumers. In this case, the actual survey return rate would be 31.2% (483/1,150). The 483 surveys returned represents 8.2% of the estimated 5,900 PLWH in the county who are presumed to be aware of their serostatus.

Distribution site codes on each survey allowed Public Health to track return rates. Table 3 shows a breakdown of survey returns by type of distribution site.

Table 3. Consumer Survey Returns by Distribution Site (N=483)

Type of Site	# Returned	% of Total
AIDS organizations/agencies	223	46%
Medical center or hospital clinics	120	25%
AIDS residential or care facilities	46	10%
Non-Western medical facilities	24	5%
Community health center or clinics	22	5%
Private doctors' offices	17	4%
Other social service agencies	14	3%
Substance use recovery programs	6	1%
Private dentists' offices	1	<1%
Site code missing/removed	10	2%
TOTAL	483	100%

Provider Surveys: Public Health delivered a total of 432 provider surveys to a wide spectrum of HIV/AIDS care providers throughout the county. These included primary care providers, case managers, mental health and substance use treatment professionals, non-Western care practitioners, private dentists and other social service providers. The Planning Council received a total of 182 valid responses, for a return rate of 42.1%.

The survey asked respondents to identify the nature of the specific service that they provided to persons living with HIV/AIDS. Table 4 shows a breakdown of surveys received from different types of providers.

Table 4. Provider Survey Returns by Provider Type (N=182)

Service Provided	# Returned	% of Total
Western medical care	60	33%
Case management	30	16%
Mental health therapy	25	14%
Dental care	12	7%
Housing related services	11	6%
Emotional support programs	8	4%
Adult day health programs	7	4%
Client advocacy/referral services	7	4%
Practical support services	6	3%
Substance abuse services	4	2%
Alternative, non-Western therapies	1	<1%
Other	10	5%
No answer	1	<1%
TOTAL	182	100%

B. Consumer Survey: General Demographics

In general, demographic responses on the consumer survey suggest a fairly representative sampling of PLWH in King County (Table 5). Survey response information was compared to PLWH demographic estimates generated by Public Health's HIV/AIDS Epidemiology Program in order to compare respondents with the overall population of PLWH in King County.

Although the Planning Council placed emphasis on collecting information from a wide range of PLWH, it also sought to over-sample traditionally under-served populations. These include homeless persons, PLWH with substance use histories, women, PLWH of color, youth/young adults, and PLWH with histories of incarceration. Although the largest single response group was white MSM (53% of total), a higher proportion of persons of color, women, persons reporting MSM/IDU transmission, and non-Seattle King County residents responded to the survey than is represented among current King County HIV prevalence estimates.

Sex: Males accounted for 84% of the survey responses, females for 14% and transgendered persons for 2% (10 male-to-female respondents, and 1 female-to-male). These percentages are similar to those on the 2001 survey. The overall prevalence estimates in King County are 91% male and 9% female.

Race: The survey asked respondents to check all applicable racial and ethnic categories. Response rates indicate that the survey effectively over-sampled persons of color as compared to the estimated King County PLWH population. White PLWH comprised 60% of respondents, compared to 73% of estimated King County PLWH. Thirteen percent of respondents identified as African-American (versus 15% of estimated PLWH), 12% Latino/Latina (8% of estimated PLWH), 2% American Indian/Alaska Native (2% of estimated PLWH) and 5% Asian/Pacific Islander (2% of estimated PLWH). Two percent of respondents identified as African, 5% identified as mixed race and 2% listed other races/ethnicities. These figures represent an 11% increase over the 2001 survey in the percentage of survey respondents who reported themselves as non-White or mixed race.

Place of residence: Eighty percent of survey respondents listed Seattle as their place of residence. Four percent of respondents live in East King County, 12% in South King County, and 4% in North King County. These percentages are relatively similar to those from the 2001 consumer survey. Among reported King County PLWH, 85% are assumed to be Seattle residents, with 15% residing in other areas of the county.

Age: Persons in the 25-29 age range are under-represented in survey responses (6% of respondents versus 30% of estimated PLWH), as are PLWH in their 30's (31% of respondents versus 44% of prevalence estimates). Conversely, persons between the ages of 40-49 are over-represented (38% versus 19%), as well as persons 50 and over (23% versus 6%). This may be due to the fact that younger persons living with HIV are generally less likely than older individuals to be aware of their serostatus, and thus would not have completed the survey. Despite outreach efforts, younger PLWH may not have received copies of the survey or may not have returned completed surveys. A higher percentage of 2003 respondents were 40 years old or older as compared to 2001 respondents (61% versus 51%).

Exposure category: The survey asked respondents to check all potential modes of transmission that they believe might have been responsible for their HIV infection. Reflective of epidemic patterns in King County, survey respondents were most likely to report HIV transmission due to male/male sexual activity (63%). Thirteen percent of respondents reported sharing drug needles as well as male/male sex. King County HIV prevalence estimates for these exposure categories are 70% MSM and 10% MSM/IDU.

Seven percent of respondents reported needle sharing exclusive of MSM activity, equal to King County PLWH estimates. A similar percentage of survey respondents reported potential transmission risk through heterosexual contact as appears in case statistics (4% of respondents versus 5% of PLWH estimates). Respondents to the 2003 survey were more likely to report MSM/IDU transmission risk than in 2001 (13% versus 9%) and less likely to report heterosexual transmission risk (4% versus 12%).

Primary language: Eighty-seven percent of consumer survey respondents reported that English was their primary language. Eight percent of respondents were primarily Spanish speakers. Four percent reported being primary speakers of other languages. The most common languages mentioned include a variety of African dialects, including Swahili and Amharic. Information regarding primary language is not available for comparison with King County PLWH estimates.

Born in the United States: Eighty-two percent of consumer survey respondents reported that they were born in the United States. Eighteen percent of respondents were born in other countries. Of the respondents who reported that they were not native United States residents, 82% had lived in the United States for six years or more. Nine percent of non-US born respondents had lived in the United States for two years or less. Information regarding country of origin is not available for comparison with King County PLWH estimates.

Other demographic indicators:

- Ten percent of respondents reported having dependent children (a 2% increase from 2001).
- Seventeen percent reported being currently homeless or without a permanent place of residence at some time during the past year (a 6% increase from 2001).
- Eight percent reported being in jail or prison in the past year (a 1% increase from 2001).

Table 5. Demographic Comparison of 2003 Consumer Survey Respondents and King County PLWH Estimates

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=483)		KC PLWH ESTIMATES (N=8,400)
	Number	Percent	Percent
SEX (n=475)			
Male	399	84%	91%
Female	65	14%	9%
Transgendered (M-to-F)	10	2%	N/A
Transgendered (F-to-M)	1	<1%	N/A
RACE (n=466)			
African	11	2%	N/A
Asian/Pacific Islander	21	5%	2%
Black/African-American	59	13%	15%
Latino/Latina	56	12%	8%
Native American/Alaska Native	10	2%	2%
White/Caucasian	279	60%	73%
Other	9	2%	N/A
Mixed race	21	5%	N/A
PLACE OF RESIDENCE (n=472)			
Seattle	378	80%	85%
East King County	20	4%	Other KC: 15%
South King County	55	12%	
North King County	18	4%	

Table 5 (continued)

Table 6 (continued)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=483)		KC PLWH ESTIMATES (N=8,400)
	Number	Percent	Percent
AGE (n=473)			
13 and under	0	0%	<1%
14-24	14	3%	13-19: 2%
25-29	28	6%	20-29: 30%
30-39	146	31%	44%
40-49	178	38%	19%
50 and over	107	23%	6%
EXPOSURE CATEGORY (n=472)			
Male/male sex (non-IDU)	299	63%	70%
Injection drug use (non-MSM)	32	7%	7%
IDU and male/male sex	63	13%	10%
Heterosexual contact	20	4%	5%
Transfusion/blood products	12	3%	1%
Parent at risk/has HIV	1	<1%	<1%
Don't know	33	7%	Don't know/ other: 6%
Other	12	3%	
PRIMARY LANGUAGE (n=474)			
English	413	87%	N/A
Spanish	40	8%	
Other	21	4%	
BORN IN THE UNITED STATES (n=474)			
Yes	389	82%	N/A
No	85	18%	
OTHER DEMOGRAPHIC CHARACTERISTICS (n=483)			
Have dependent children	50	10%	N/A
Homeless (current or in past	82	17%	N/A
In jail/prison (current or in past	36	8%	N/A

C. Consumer Survey: Medical and Health Indicators

The consumer survey asked respondents about a variety of HIV-related medical and other health indicators. This information offers additional insights about the HIV health status of the consumers who responded to the survey, as well as providing information about the extent of other co-morbidities in the cohort that may impact their overall health.

AIDS disability: The survey asked if respondents had received doctor certification of AIDS-related disability. Sixty-one percent of respondents reported that they received certification of disability, and 31% reported that they had not. Eight percent of respondents were unsure if a doctor had certified them as AIDS disabled. (Table 6)

Table 6. Consumer Survey: Medical and Health Indicators

	Number	Percent
CERTIFIED BY DOCTOR AS “AIDS DISABLED” (n=474)		
Yes	291	61%
No	147	31%
Don’t know	36	8%
LAST T-CELL COUNT (n=474)		
Under 200	116	25%
201 – 500	213	45%
Over 500	92	19%
Don’t know	53	11%
LAST VIRAL LOAD (n=472)		
Undetectable/below 70	185	39%
Between 70 – 1000	70	15%
1001 – 10,000	69	15%
10,001 – 100,000	58	12%
Over 100,000	28	6%
Don’t know	62	13%
HIV MEDICATIONS (n=483)		
Taking antiviral medications	347	72%
Taking protease inhibitors	226	47%
Taking meds to treat or prevent OI’s	172	36%
Taking meds to manage HIV side effects	185	38%

Table 6 (continued)

	Number	Percent
EVER DIAGNOSED WITH A MENTAL ILLNESS (n=460)		
Yes	254	55%
No	206	45%
DRUG USE HISTORY (n=483)		
Injection drug use history	95	20%
Used non-injectable drugs(past year)	182	38%
TYPES OF NON-INJECTABLE DRUGS USED (n=483)		
Marijuana (for non-medical purposes)	28	28%
Methamphetamine	57	12%
Cocaine	53	11%
Poppers/inhalants	49	10%
Ectasy	25	5%
Downers	20	4%
Party drugs (GHB/K/etc.)	12	2%
ALCOHOL PROBLEMS IN PAST YEAR (N=483)		
Yes	97	20%
No	386	80%

Sex appears to be correlated with AIDS-related disability in the respondent population. Among consumer sub-populations, males were significantly more likely than females to have been certified as AIDS disabled (65% versus 43%). No other variables (e.g., race, place of residence, age, IDU status) assumed statistical significance in relation to disability status.

Latest T-cell counts: One quarter of consumer respondents reported having T-cell counts under 200, the clinical marker for AIDS diagnosis. Forty-five percent reported having T-cell counts in the 201-500 range, and 19% reported T-cell counts over 500. Eleven percent of respondents did not know the results of their most recent T-cell test.

No significant differences emerged regarding the percentage of various consumer sub-populations reporting T-cell counts under 500. However, MSM were significantly more likely than other populations to report T-cell counts over 500 (24% versus 11% of non-MSM). Persons of color across all non-White categories were significantly more likely than Whites to be unaware of their T-cell count (21% versus 5%). Several other variables were also associated with not knowing one's T-cell counts: being female (20% versus 9% of males), homeless (21% versus 9% of non-homeless PLWH) and/or incarcerated in the past year (22% versus 10% of non-incarcerated).

Latest viral loads: Approximately two-fifths of all respondents reported having undetectable viral loads. Fifteen percent reported having viral loads between 70-1,000; 15% reported viral loads between 1,001-10,000; 12% reported viral loads between 10,001-100,000 and 6% reported

viral loads over 100,000. Thirteen percent of respondents did not know the results of their most recent viral load test.

No significant differences emerged regarding the percentage of various consumer sub-populations reporting viral loads over 1,000. Several sub-populations were significantly less likely to report undetectable viral loads: homeless PLWH (16% reporting undetectable viral loads versus 44% of non-homeless), youth and young adults (7% versus 40% of PLWH over the age of 24) and PLWH who had been incarcerated in the past year (18% versus 41% of non-incarcerated). MSM were three times more likely than non-MSM to be aware of their viral loads (8% of MSM not knowing their viral load versus 27% of non-MSM). Other variables associated with not knowing one's viral load included being female (25% versus 11% of males), homeless (23% versus 11% of non-homeless PLWH), incarcerated in the past year (24% versus 11% of non-incarcerated), and of non-White race/ethnicity (21% versus 6% of Whites).

HIV medications: Seventy-two percent of consumers reported currently taking some form of antiviral medications. (Table 7) This represents a statistically significant decrease from the 79% of consumers who reported taking antiviral medications on the 2001 survey. The percent of consumers who reported taking protease inhibitors has also decreased (from 53% to 47%) as has the percentage of PLWH taking drugs to treat or prevent opportunistic infections (from 43% to 37%).

Based on input from consumers in focus groups and key informant interviews with providers, it appears that the decrease in the percentage of PLWH on antiretrovirals and protease inhibitors is related to several factors. These include clients choosing to no longer take medications after having taken them for several years, clients deciding to discontinue medications due to negative side effects, and clients delaying starting antiviral treatments.

Table 7: Current Medication Status

CONSUMERS CURRENTLY TAKING HIV-RELATED MEDICATIONS:			
	<u>2003</u>	<u>2001</u>	<u>1999</u>
On antiretroviral medications	72%	79%	69%
On protease inhibitors	47%	53%	60%
On other drugs to treat/prevent OI	37%	43%	51%

Mental health status: Fifty-five percent of survey respondents report that they had ever been diagnosed with a mental illness, including clinical depression. This represents an 8% increase over 2001 survey respondents. Injection drug using PLWH were significantly more likely than non-IDU to report having been diagnosed with mental illness (79% versus 48%), as were PLWH who had been homeless in the past year (70% versus 52% of non-homeless). Although the overall population of MSM survey respondents were no more likely than non-MSM to report mental illness, White MSM were significantly more likely to do so than MSM of color (59% to 40%).

History of drug use: Twenty percent of consumer respondents reported some form of drug use

history. Survey respondents were considered to have had a drug use history if they (a) reported having used injection and/or non-injection drugs in the past year, (b) became HIV positive through injection drug use or (c) reported using injection drug use treatment or counseling services. Eight percent of the survey population had injected drugs in the past year and 46% reported some form of non-injection drug use.

The most common non-injectable drugs that consumers reported using were marijuana (for non-medical reasons) (28% of all respondents), methamphetamine (12%), cocaine (11%), and poppers or inhalants (10%). White MSM were more likely than other populations to have used marijuana (35% versus 23% of MSM and color and 15% of non-MSM) and methamphetamine (16% versus 9% and 4%, respectively). Poppers were almost exclusively used by MSM, as compared to non-MSM PLWH (13% versus 1%). Homeless PLWH and PLWH with histories of incarceration were more likely to use the full spectrum of injectable and non-injectable drugs than PLWH without these histories.

Alcohol problems: Consumers were considered to have had alcohol problems in the past year if they answered “yes” to any of the following four questions:

In the past twelve months, have you:

- Tried to cut down on drinking alcohol?
- Had family/friends tell you they were annoyed or upset by your drinking?
- Used alcohol in the morning to feel better?
- Felt guilty about your drinking or your behavior when using alcohol?

Based on a “yes” answer to one or more of these questions, 20% of the survey population was determined to have had alcohol problems in the past year. The consumer sub-populations that were significantly more likely to report alcohol problems included PLWH with histories of incarceration (58%) and those who had been homeless in the past year (31%).

D. Provider Survey: Client Demographics

The survey asked providers about the total number of clients with HIV/AIDS on their active caseload and asked them to characterize their HIV/AIDS clientele by several demographic indicators. Averaging valid responses from all returned surveys derived percentages for each of the demographic characteristics. Based on response to these demographic questions, it appears that the client population served by provider survey respondents is fairly representative of PLWH in King County (Table 8). Efforts to over-sample among providers who serve women, persons of color, and non-MSM proved successful based on demographic frequencies.

Total caseload: The average caseload reported by providers is 111 clients, with a range of one to 1,200. Among the most common provider types, primary medical care providers (n=60) reported average caseloads of 115 clients, case managers (n=30) reported average caseloads of 78 clients, and mental health providers (n=25) reported average caseloads of 48.

Sex: The average client caseload among responding providers was 84% male, 15% female and

1% transgendered. These figures are relatively similar to those reported by providers in 2001. HIV prevalence estimates in King County are 91% male and 9% female.

Race: The racial breakdown of the average provider caseload was 65% White and 35% persons of color, as compared to King County PLWH estimates of 73% and 27%, respectively. This represents a 6% increase in the average percentage of clients who are persons of color as compared to 2001 survey responses. Within non-White categories, most provider caseload percentages and King County estimates were relatively similar, with providers reporting that 14% of their clients were African-American (KC estimate: 15%), 3% Asian/Pacific Islander (KC estimate: 2%), and 2% American Indian/Alaska Native (KC estimate: 2%). Provider survey respondents reported a higher percentage of clients who were Latino/a than among King County PLWH estimates (11% versus 8%).

Age: Similar to consumer survey percentages, provider caseloads were more likely to over-represent clients aged 40 and older and somewhat less likely to represent PLWH between the ages of 25-39. Less than one percent of clients served were under the age of 13, similar to King County PLWH estimates. Four percent of provider caseloads were between the ages of 13-24 and 15% were between the ages of 25-29. King County uses different breakpoints in classifying PLWH age ranges, with 2% of clients in the 13-19 age range and 30% between the ages of 20-29. Thirty-eight percent of survey respondents were in their 30's (KC estimate: 44%), 31% in their 40's (KC estimate: 19%) and 11% age 50 and over (KC estimate: 6%). Providers in 2003 were less likely than in 2001 to report adolescent and young adult clients (4% versus 12%), but more likely to report seeing clients over the age of 40 (42% versus 28%).

Exposure category: The survey asked providers to classify their clients by primary modes of HIV exposure. Providers reported that 64% of their clients were exposed through male/male sex, with an additional 13% of clients dually exposed through MSM contact and injection drug use. King County PLWH estimates for these populations are 70% and 10%, respectively. Providers reported that 13% of their clients were primarily exposed through injection drug use (KC estimate: 7%). Providers reported a slightly higher percentage of clients exposed through heterosexual contact (9%) than are represented in King County PLWH estimates (5%). These figures are relatively similar to exposure category percentages in 2001, with the exception of a slightly lower percentage of IDU (13% versus 15%) and higher MSM/IDU (13% versus 9%).

Place of residence: Providers reported seeing a higher percentage of clients from non-Seattle King County than appear in King County PLWH estimates. Seventy-one percent of clients are from Seattle (KC estimate: 85%), 6% from East King County, 11% from South King County and 5% from North King County (KC estimate: 15% from non-Seattle King County). The remaining 6% of clients served reside outside King County, but receive services from King County-based providers. The percent of clients reported living outside Seattle has increased from 23% in 2001 to 29% in 2003.

Primary language: Providers reported that 89% of their clients are primarily English speaking, with 7% being primarily Spanish-speaking and 4% being primary speakers of other languages. This represents almost a twofold increase from the 2001 survey in the percentage of non-English speaking clients. The most common other languages spoken by clients are various African dialects (including Amharic, Eritrean, Swahili, etc.) and, to a lesser extent, Asian languages

(Thai, Vietnamese, Chinese, etc.). In 2001, 17% of all providers reported seeing one or more clients who were primary speakers of languages other than English or Spanish. In 2003, this figure has risen to 23% of all providers, suggesting an overall increase in the number of non-English/non-Spanish speakers, as well as increased utilization of a wider spectrum of services across the Continuum of Care by these clients.

Other demographic indicators: On average, providers reported decreased percentages of other medical or social co-morbidities than in 2001. In 2003, providers reported that:

- Thirteen percent of their clients are currently homeless or have been without a permanent place of residence within the past year (down from 15% in 2001)
- Ten percent have been in jail or prison in the past year (down from 11% in 2001)
- Thirty-four percent have been diagnosed with a mental illness (down from 47% in 2001)
- Thirty-seven percent have a history of chemical dependency (down from 46% in 2001).

It should be noted that providers in key informant interviews stressed that the overall severity of these co-morbidities has increased in the past several years, despite the drop in the percentage of clients being reported with these conditions.

Table 8. Demographic Comparison of 2003 Provider Survey Client Demographics and King County PLWH Estimates

Characteristics	Client Demographics From Provider Surveys (N=182)	KC PLWH Estimates (N=8,400)
Average client caseload = 111		
SEX		
Male	84%	91%
Female	15%	9%
Transgendered (M-to-F)	1%	N/A
Transgendered (F-to-M)	<1%	N/A
RACE		
African	3%	N/A
Asian/Pacific Islander	4%	2%
Black/African-American	14%	15%
Latino/Latina	11%	8%
Native American/Alaska Native	2%	2%
White/Caucasian	65%	73%
Other	1%	N/A
PRIMARY LANGUAGE		
English	89%	N/A
Spanish	7%	
Other	4%	
AGE		
<13	<1%	<1%
13-24	4%	13-19: 2%
25-29	15%	20-29: 30%
30-39	38%	44%
40-49	31%	19%
50 and over	11%	6%
EXPOSURE CATEGORY		
Male/male sex	64%	70%
Injection drug use (non-MSM)	13%	7%
IDU and male/male sex	13%	10%
Heterosexual contact (non-IDU)	9%	5%
Parent at risk/has HIV	<1%	<1%
Other/Unknown	2%	6%

Table 8 (continued)

Characteristics	Client Demographics From Provider Surveys (N=182)	KC PLWH Estimates (N=8,400)
PLACE OF RESIDENCE		
Seattle	71%	85%
East King County	6%	Other KC: 15%
South King County	11%	
North King County	5%	
Outside King County	6%	
OTHER DEMOGRAPHIC CHARACTERISTICS		
Homeless (in past year)	13%	N/A
In jail or prison (in past year)	10%	N/A
History of chemical dependency	37%	N/A
Diagnosed w/mental illness	34%	N/A

E. Service Priorities

Consumer-identified priorities: The consumer survey included a one-page list of the 32 types of HIV/AIDS-related services offered in the King County Continuum of Care. The survey asked consumers to identify up to seven services that they considered as most important in helping them cope with HIV/AIDS-related health issues (“service priorities”). Responses were collapsed into the 22 Planning Council-identified Ryan White service categories shown below, and ranked by overall percentage of response. (See Appendix F for services listed on the survey and their associated Ryan White funding categories). Table 9 includes cumulative responses of service priorities.

Consumers ranked ambulatory medical care as the highest service priority, with two-thirds of respondents stating that it was a priority for them. Medical care was followed by oral health care, AIDS Drug Assistance Program, case management, and housing assistance as the top five service priorities. Among the component services within the housing category, consumers were more likely to prioritize help paying rent (42%) than help finding housing (19%).

AIDS-related disability status appears to have relatively little impact on most service categories, either in the rank order or overall percentage of consumers who reported it as a priority. In terms of gaining access to continuum-wide services, PLWH who were AIDS-disabled were significantly more likely to prioritize case management (63% versus 50%), while persons who were not disabled by AIDS were significantly more likely to identify client advocacy services as a priority (32% versus 18%). Consumers who were AIDS-disabled were generally more likely than non-disabled respondents to prioritize assistance with activities of daily living, such as food

and meal programs (37% versus 27%), transportation (23% versus 10%) and home health care (7% versus 2%).

Sub-population specific differences in consumer service priorities are discussed in each of the chapters in Part V, Specific Population Findings.

**Table 9. Service Priorities from Consumer Surveys
(N=467; 16 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	308	66%
2	Oral health care	287	61%
3	AIDS Drug Assistance Program	275	59%
4	Case management	266	57%
5	Housing assistance/related services	234	50%
6	Emergency financial assistance	222	48%
7	Health insurance	190	41%
8	Food bank/home-delivered meals	153	33%
9	Psychosocial support	148	32%
10	Mental health services	142	30%
11	Alternative, non-Western therapies	109	23%
12	Client advocacy	105	22%
13	Legal services	93	20%
14	Transportation	85	18%
15	Day/respite care for adults	51	11%
16	Referral for health care services	49	10%
17	Substance abuse services	35	7%
18	Treatment adherence support	33	7%
19	Health education/risk reduction	25	5%
20	Buddy/companion care	23	5%
21	Home health care	22	5%
22	Child care	20	4%

Comparison between 2001 and 2003 consumer service priorities: Service priority rankings

changed little between 2001 and 2003 (Table 10). Only four of the twenty-two comparable service categories moved up or down three or more places in overall consumer priority ranking over the past two years. In terms of the overall percentage of consumers who prioritized each service, three services increased significantly and three decreased significantly.

**Table 10. Comparison Between 2001 and 2003
Consumer-Identified Service Priorities**

Service	2001 (N=511)		2003 (N=467)	
	Rank	%	Rank	%
AIDS Drug Prescription Program	6	40%	3	59%
Alternative/non-Western therapies	9	29%	11	23%
Ambulatory/outpatient medical care	1	63%	1	66%
Buddy/companion care	19	8%	20	5%
Case management	3	50%	4	57%
Child care	22	2%	22	4%
Client advocacy	7	35%	12	22%
Day/respite care for adults	15	10%	15	11%
Emergency financial assistance	8	31%	6	48%
Food bank/home-delivered meals	10 (tie)	29%	8	33%
Health education/risk reduction	21	4%	19	5%
Health insurance	5	41%	7	41%
Home health care	17	9%	21	5%
Housing assistance/related services	4	47%	5	50%
Legal services	13	16%	13	20%
Mental health services	10 (tie)	29%	10	30%
Oral health care	2	56%	2	61%
Psychosocial support	12	28%	9	32%
Referral for health care services	16	10%	16	10%
Substance abuse services	18	9%	17	7%
Transportation	14	14%	14	18%
Treatment adherence support	20	6%	18	7%

The AIDS Drug Assistance Program, ranked as the sixth highest consumer priority in 2001, rose

to the third highest priority and represents the largest overall percentage increase (ranked as a priority by 40% of consumers in 2001 and 59% in 2003). Emergency financial assistance also significantly increased as a consumer priority, up seventeen percentage points from 31% in 2001 to 48% in 2003. Case management also increased significantly as a consumer identified priority (50% in 2001; 57% in 2003).

Client advocacy programs, including peer advocacy, education about HIV/AIDS and interpreter services, assumed both the greatest ranking and percentage decreases. This service category was ranked as the seventh highest consumer priority in 2001 (35% of consumers identifying it as a priority service), but dropped to twelfth overall in 2003 (22%). Other significant percentage decreases occurred in alternative therapies (29% in 2001; 23% in 2003) and home health care (9% versus 4%).

Provider-identified service priorities: The provider survey included the same one-page list of 32 types of HIV/AIDS-related services as was included in the consumer version. The survey asked each responding provider to identify up to seven services that they considered most important in helping their clients cope with HIV/AIDS-related health issues. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 11 reports cumulative responses of provider priorities.

In order to ensure that provider-identified priorities were not biased by over-sampling certain types of providers (i.e., medical providers and case managers), additional data runs were conducted controlling for provider type. Analysis revealed that provider type did not significantly skew identification of priorities or gaps.

Providers ranked case management as the highest service priority for their clients, followed by the AIDS Drug Assistance Program, ambulatory medical care, mental health services, and housing services. Among the component services within the housing category, providers were more likely to prioritize help finding housing (36%) than help paying rent (17%).

**Table 11. Service Priorities from Provider Surveys
(N=178; 4 missing/invalid responses)**

Rank	Service	Total Votes	%
1	Case management	145	81%
2	AIDS Drug Assistance Program	135	76%
3	Ambulatory/outpatient medical care	129	72%
4	Mental health services	120	67%
5	Housing assistance/related services	84	47%
6	Health insurance	69	39%
7	Substance abuse services	60	34%
8	Day/respite care for adults	56	31%
9	Psychosocial support	45	25%
10	Client advocacy	42	24%
11	Oral health care	41	23%
12	Transportation	37	21%
13	Treatment adherence support	25	14%
14	Alternative, non-Western therapies	21	12%
15	Emergency financial assistance	20	11%
16	Food bank/home-delivered meals	18	10%
17	Health education/risk reduction	14	8%
18	Referral for health care services	9	5%
19 (tie)	Home health care	8	4%
19 (tie)	Legal services	8	4%
21	Buddy/companion care	5	3%
22	Child care	4	2%

Comparison between 2001 and 2003 provider-identified service priorities: Provider priority rankings and percentages demonstrated greater changes than consumer priorities during the past two years (Table 12). Six out of twenty-two service categories moved up or down three or more places in priority rankings from 2001 to 2003, and eight service categories demonstrated significant increases or decreases.

**Table 12. Comparison Between 2001 and 2003
Provider-Identified Service Priorities**

Service	2001 (N=251)		2003 (N=178)	
	Rank	%	Rank	%
AIDS Drug Assistance Program	4	55%	2	76%
Alternative/non-Western therapies	16 (tie)	10%	14	12%
Ambulatory/outpatient medical care	1	76%	3	72%
Buddy/companion care	20	5%	21	3%
Case management	2	68%	1	81%
Child care	21 (tie)	2%	22	2%
Client advocacy	7	39%	10	24%
Day/respite care for adults	13	18%	8	31%
Emergency financial assistance	18	10%	15	11%
Food bank/home-delivered meals	15	12%	16	10%
Health education/risk reduction	16 (tie)	10%	17	8%
Health insurance	10	23%	6	39%
Home health care	14	16%	19 (tie)	4%
Housing assistance/related services	6	41%	5	47%
Legal services	19	9%	19 (tie)	4%
Mental health services	3	63%	4	67%
Oral health care	11 (tie)	22%	11	23%
Psychosocial support	9	25%	9	25%
Referral for health care services	21 (tie)	2%	18	5%
Substance abuse services	5	49%	7	34%
Transportation	11 (tie)	22%	12	21%
Treatment adherence support	8	27%	13	14%

The greatest increases in priority rankings occurred in the categories of health insurance (up from 10th place in 2001 to 6th in 2003) and in day/respite care (adult day health programs) (13th in 2001; 8th in 2003). Providers noted that the increasing costs of HIV care and treatments, coupled with the elimination of private insurance programs for PLWH in Washington State, have made it more necessary than ever to ensure that their clients have effective medical coverage. Providers also noted the increasing importance of adult day health programs in helping their

medically-needy and multiply-diagnosed clients cope with health and medication adherence issues.

The AIDS Drug Assistance Program showed the greatest percentage increase among provider priorities, increasing from 55% of providers who prioritized the service in 2001 to 76% in 2003.

This may reflect the number of providers whose clients are now on HAART medications, as well as a growing number of non-medical providers who discuss medication and adherence issues with their clients. Other services that demonstrated significant percentage increases include health insurance (23% in 2001; 39% in 2003), day/respite care (18% in 2001; 31% in 2003) and case management (68% in 2001; 81% in 2003).

Services which dropped three or more places in the overall provider priority rankings included client advocacy (down from 7th place in 2001 to 10th place in 2003), treatment adherence support (8th in 2001; 13th in 2003) and home health care (14th in 2001; 19th in 2003). As their clients continue to exhibit increasingly severe co-morbidities (mental health and substance use) and complex life challenges (homelessness, incarceration, immigration status), the need for professional case management has increased, while the need for peer advocacy has lessened. This is demonstrated by a significant increase in the percentage of providers who prioritized case management (up from 68% in 2001 to 81% in 2003).

Treatment adherence support as a stand-alone program has dropped as an overall priority as more providers have incorporated it into their standard service delivery. This change may in part be due to Planning Council funding caveats regarding adherence support that were placed on several service categories in recent funding years (i.e., primary medical care, case management and psychosocial support).

Of note is the significant decrease in the percentage of providers who prioritized substance abuse services. In 2001, almost half of all providers (49%) listed this service as one of the most important services for their clients. In 2003, only 34% of providers prioritized this service. Several factors may have contributed to this decrease:

- increasingly limited treatment options, due to the closure of several local programs in the past few years (including the elimination of in-patient services at Cedar Hills, targeted gay/lesbian/bisexual substance use treatment programs at Stonewall Recovery Service);
- providers sensing that substance use treatment is less of a priority from their clients' perspectives;
- provider sentiments that it may be more feasible to deal with the mental health manifestations of substance use, rather than wait for treatment to become available, and
- a drop in the overall number and percentage of provider survey respondents who were substance use providers (sixteen substance use providers (6% of total) in 2001 versus four substance use providers (2% of total) in 2003), although this factor would have had limited impact on overall rankings.

Comparison between 2003 consumer and provider service priorities: Comparisons between consumer and provider responses yield numerous differences in both priority rankings and percentages. (Table 13) Statistically significant percentage differences emerged in almost half of

all services under consideration. As in previous years, providers were more likely to prioritize clinical services, while consumers were more likely to prioritize ancillary services, particularly those that provide financial and practical support.

Significant disparities are visible even in those service categories that both consumers and providers rank among their top priorities. Although both groups assign high priority to case management (consumer rank: 4; provider rank: 1) and the AIDS Drug Assistance Program (consumer rank: 3; provider rank: 2), the relative importance placed on these services is quite different. Eighty-one percent of providers ranked case management as a service priority, versus 57% of consumers. Seventy-six percent of providers ranked ADAP as a service priority, versus 59% of consumers.

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance use treatment and mental health counseling as service priorities. This trend continues in 2003, with even greater disparity between the two groups. Providers were approximately five times more likely than consumers to prioritize substance use treatment (34% versus 7%) and over twice as likely to prioritize mental health counseling (67% versus 30%). These discrepancies were also noted by providers during the key informant interview process, many of whom reported increased severity of their dually and triply diagnosed clients (HIV/mental illness/chemical dependency), coupled with client resistance to and/or lack of access to these services.

Consumers were significantly more likely than providers to assign priority to alternative/non-Western therapies (23% versus 10%), oral health care (61% versus 23%), emergency financial assistance (48% versus 11%), food and meal programs (33% versus 10%) and legal services (20% versus 4%). Previous needs assessments revealed similar disparities, and the percentage difference between consumer and provider perceptions of these services appears to have increased in the past two years.

**Table 13. Comparison Between
Consumer and Provider Identified Service Priorities**

Service	Consumer (N=467)		Providers (N=178)	
	Rank	%	Rank	%
AIDS Drug Assistance Program	3	59%	2	76%
Alternative/non-Western therapies	11	23%	14	12%
Ambulatory/outpatient medical care	1	66%	3	72%
Buddy/companion care	20	5%	21	3%
Case management	4	57%	1	81%
Child care	22	4%	22	2%
Client advocacy	12	22%	10	24%
Day/respite care for adults	15	11%	8	31%
Emergency financial assistance	6	48%	15	11%
Food bank/home-delivered meals	8	33%	16	10%
Health education/risk reduction	19	5%	17	8%
Health insurance	7	41%	6	39%
Home health care	21	5%	19 (tie)	4%
Housing assistance/related services	5	50%	5	47%
Legal services	13	20%	19 (tie)	4%
Mental health services	10	30%	4	67%
Oral health care	2	61%	11	23%
Psychosocial support	9	32%	9	25%
Referral for health care services	16	10%	18	5%
Substance abuse services	17	7%	7	34%
Transportation	14	18%	12	21%
Treatment adherence support	18	7%	13	14%

F. Service Gaps

Consumer-identified service gaps: As previously noted, the survey asked consumers to identify each of the 32 services offered in the King County Continuum of Care as ones that they needed and used, did not need, or needed but could not get. Each service that a consumer identified as “needed, but could not get” is considered a service gap. These responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Cumulative categorical service gap responses appear in Table 14.

As in previous surveys, consumers identified very few of the services available in the Seattle-King County Continuum of Care as being grossly deficient or inaccessible. Several differences emerged, however, when comparing responses among specific sub-populations. (These will be discussed in the population-specific information found in Section V.)

Consistent with previous years, consumers considered lack of emergency financial assistance as the number one service gap. Approximately one-third of survey respondents noted this gap. Among the sub-components of this service category, 27% identified a gap in obtaining grocery vouchers and 21% of respondents identified a gap in help paying utility bills. These results are not surprising, given the very low income levels traditionally reported by a large percentage of consumers. Providers noted that, for many of their clients, financial problems such as these pre-date the clients’ HIV diagnoses and are further complicated by the onset of disease.

Other top five ranked service gaps include housing services, psychosocial support, legal services and alternative/non-Western therapies. Within the housing category, consumers identified a larger gap in help paying rent (21%) than in help finding housing (12%). Within the psychosocial support category, one-to-one peer support was the largest gap (16%), followed by support groups (8%) and spiritual and religious counseling (8%).

Few significant differences emerged in service gap identification based on disability status. In four categories, however, persons who were not disabled by HIV/AIDS identified significantly greater gaps than those who reported themselves as having received certification of disability from their doctors. These categories include housing services (29% of non-disabled PLWH versus 21% of disabled PLWH); psychosocial support (27% versus 17%), case management (11% versus 4%) and health insurance (12% versus 5%).

Based on guidance from the HIV/AIDS Housing Committee, AIDS-defining disability remains one of the eligibility criteria for placement in transitional and permanent AIDS housing. This is due largely to resource limitations in the number of units available within the HIV system, and a critical housing shortage in King County in general. Consumers who are not disabled by HIV are eligible for emergency rental assistance and placement in emergency shelter, but they may be more likely to identify a gap in their access to transitional and permanent housing. The availability of services in each of the three other categories mentioned (psychosocial support, case management and health insurance) is not predicated on disability status. However, non-disabled consumers may feel that their needs are not as well addressed for these services as they are for disabled consumers.

Table 14. Service Gaps from Client Surveys (N=483)

Rank	Service	Total Votes	%
1	Emergency financial assistance	166	34%
2	Housing assistance/related services	115	24%
3	Psychosocial support	101	21%
4	Legal services	89	18%
5	Alternative, non-Western therapies	86	18%
6	Oral health care	83	17%
7	Client advocacy	67	14%
8	Mental health services	66	14%
9	Food bank/home-delivered meals	61	13%
10	Referral for health care services	46	10%
11	Buddy/companion care	44	9%
12	AIDS Drug Assistance Program	38	8%
13	Transportation	35	7%
14	Health insurance	34	7%
15	Child care	32	7%
16	Case management	29	6%
17	Home health care	24	5%
18	Day/respite care for adults	21	4%
19	Health education/risk reduction	19	4%
20	Treatment adherence support	18	4%
21	Substance abuse services	18	4%
22	Ambulatory/outpatient medical care	9	2%

Comparison between 2001 and 2003 consumer-identified service gaps: The percent of consumers who identified service gaps rose in seventeen of the twenty-two categories from 2001 to 2003 (Table 15). In most cases, the increases were minimal and not statistically significant. These results may be due to several factors, depending on the service category. In some instances, the gap may be ongoing and ultimately insurmountable, as with financial assistance, in which Ryan White funds are incapable of fulfilling consumer need. In others, it may suggest that a prior gap has been filled and a new one has arisen, either due to emerging consumer sub-populations or newly identified needs. This may be true of a category such as legal services, in which fewer consumers are seeking estate planning but greater numbers are in need of

immigration assistance.

**Table 15. Comparison Between 2001 and 2003
Consumer-Identified Service Gaps**

Service	2001 % (N=538)	2003 % (N=483)
AIDS Drug Assistance Program	5%	8%
Alternative/non-Western therapies	22%	18%
Ambulatory/outpatient medical care	1%	2%
Buddy/companion care	7%	9%
Case management	4%	6%
Child care	1%	7%
Client advocacy	20%	14%
Day/respite care for adults	5%	4%
Emergency financial assistance	24%	34%
Food bank/home-delivered meals	10%	13%
Health education/risk reduction	3%	4%
Health insurance	6%	7%
Home health care	5%	5%
Housing assistance/related services	19%	24%
Legal services	11%	18%
Mental health services	10%	14%
Oral health care	15%	17%
Psychosocial support	20%	21%
Referral for health care services	9%	10%
Substance abuse services	4%	4%
Transportation	3%	7%
Treatment adherence support	5%	4%

The highest percentage increase in identified gaps occurred in the category of emergency financial assistance. The service ranked as the highest consumer-identified gap in both 2001 and 2003, but the overall percentage of consumers noting gaps in this service rose from 24% to 34%. Within the category, 27% of consumers identified gaps in grocery vouchers and 21% identified gaps in help paying utility bills. In both of these cases, the gap may actually be more of a statement about the poverty level of many PLWH, with consumers having to juggle multiple

financial priorities on very limited (or no) income. Additionally, utility rates in King County have increased dramatically in the past few years, exacerbating consumers' need for financial assistance.

Provider-identified service gaps: The provider survey asked respondents to identify service gaps for the clients they served using the same list of 32 HIV/AIDS-related services from which priorities were identified. Each responding provider was asked to check any of the services which a substantial number of their clients needed, but had difficulty accessing. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 16 includes cumulative responses of provider-identified service gaps.

Higher percentages of providers identified gaps in services than did consumers due to the fact that providers were asked to consider a service as a "gap" if a substantial number of their clients had trouble accessing a service, while each consumer vote represents the response of a single individual. As a result, provider-identified service gaps are useful as a reflection of provider opinions about the Continuum of Care, rather than in determining a quantitative measure of service gaps for the population of PLWH in King County.

As in 1999 and 2001, providers identified housing assistance and housing related services as the number one gap for the clients they served. Within the housing category, providers were almost equally likely to identify gaps in their clients' ability to get help finding housing (39%) as gaps in getting help paying rent (36%). In key informant interviews, providers pointed to long waiting lists for subsidized housing, limited options for PLWH with families and dependent children, rising rental costs and low vacancy rates as key barriers. Many providers noted that locating housing for their clients who are active substance users and/or have criminal histories remains extremely difficult.

Providers also ranked substance abuse services, mental health services, and oral health care among the top service gaps for their HIV+ clients. This is consistent with provider reports that high percentages of their caseloads are presenting with significant substance use and mental health issues, including rising methamphetamine use among women and increasing depression and psychoses. Although many providers noted that communication and collaboration between the HIV, substance use and mental health systems has improved in recent years, they also noted that many barriers still exist in helping their clients access these services. Among the most common barriers identified were clients not wishing to avail themselves of these services, lack of insurance coverage and payment options and cultural norms in some consumer sub-populations that mental health services are only for severely mentally ill people.

Barriers to accessing oral health care are similar as for mental health: clients not engaging in preventative care and lack of insurance coverage and payment options (especially for more complex procedures). Long waiting periods for initial appointments can negatively impact client follow-through, particularly if the client is dealing with issues such as substance use, homelessness and/or has dependent children. Fewer private providers in King County are accepting Medicaid coupons for dental work, as the costs of care have increased beyond the reimbursement rates.

**Table 16. Service Gaps from Provider Surveys
(N=168; 14 missing responses)**

Rank	Service	Total Votes	%
1	Housing assistance/related services	97	58%
2	Substance abuse services	82	49%
3	Mental health services	76	45%
4	Oral health care	74	44%
5	Emergency financial assistance	58	35%
6	Psychosocial support	41	24%
7	Treatment adherence support	37	22%
8	Health insurance	34	20%
9	Client advocacy	31	18%
10	Alternative, non-Western therapies	29	17%
11 (tie)	AIDS Drug Assistance Program	27	16%
11 (tie)	Transportation	27	16%
13	Day/respite care for adults	24	14%
14	Home health care	21	13%
15	Legal services	18	11%
16	Child care	16	10%
17	Buddy/companion care	15	9%
18	Case management	12	7%
19	Health education/risk reduction	10	6%
20	Ambulatory/outpatient medical care	9	5%
21	Food bank/home-delivered meals	8	5%
22	Referral for health care services	4	2%

Comparison between 2001 and 2003 provider-identified service gaps: Several significant changes emerged between provider-identified service gaps from 2001 to 2003 (Table 17). Six of the twenty-two categories demonstrated statistically significant increases or decreases in the percentage of providers identifying service gaps.

**Table 17. Comparison Between 2001 and 2003
Provider-Identified Service Gaps**

Service	2001 % (N=253)	2003 % (N=182)
AIDS Drug Assistance Program	13%	16%
Alternative/non-Western therapies	14%	17%
Ambulatory/outpatient medical care	10%	5%
Buddy/companion care	9%	9%
Case management	11%	7%
Child care	6%	10%
Client advocacy	28%	18%
Day/respice care for adults	12%	14%
Emergency financial assistance	18%	35%
Food bank/home-delivered meals	10%	5%
Health education/risk reduction	6%	6%
Health insurance	17%	20%
Home health care	14%	13%
Housing assistance/related services	44%	58%
Legal services	13%	11%
Mental health services	30%	45%
Oral health care	27%	44%
Psychosocial support	25%	24%
Referral for health care services	3%	2%
Substance abuse services	32%	49%
Transportation	23%	16%
Treatment adherence support	21%	22%

Five service categories experienced significant increases from 2001 to 2003. These include substance abuse services (identified as a gap by 32% of providers in 2001 and 49% in 2003), oral health care (27% in 2001 and 44% in 2003), emergency financial assistance (18% in 2001; 35% in 2003), mental health services (30% in 2001; 45% in 2003) and housing related services (44% in 2001; 58% in 2003). Specific reasons for these gaps have been addressed previously in this report. It should be noted that the increase in provider-identified gaps may also be related to

increased provider awareness of client-level needs, a possible artifact of the ongoing needs assessment process.

Comparison between consumer and provider gap rankings: As in previous years, consumers and providers differed greatly in the service gaps they identified in the King County Continuum of Care. Significant differences emerged in the percentage of consumers and providers identifying gaps in 13 of the 22 Ryan White service categories, with providers being more likely than consumers to identify service gaps in 10 of these 13 categories.

It is difficult to determine if this disparity represents actual differences in consumer versus provider perceptions of service gaps, or a methodological limitation (since consumers were asked to identify personal gaps while providers were asked to identify service gaps across the entire population of clients with whom they worked). Aggregate provider response may, in fact, over-state gaps by inflating gaps for small numbers of consumers into system-wide problems. Conversely, it is possible that provider responses were more reflective of actual gaps for populations that the consumer survey may have under-sampled: housing (homeless persons), mental health therapy (mentally ill persons), substance use treatment (chemically dependent persons) and transportation (PLWH living in non-urban parts of the county).

The largest disparities in consumer and provider-identified service gaps emerged in the areas of substance abuse services, housing assistance, mental health counseling, and oral health care. Forty-nine percent of providers noted that their clients needed but could not get substance use treatment and counseling, versus only 4% of consumers. Wide disparities also occurred in the areas of mental health counseling (identified as a gap by 45% of providers, but only by 14% of consumers) and oral health care (44% of providers, 17% of consumers). In all three cases, the gap may be related to provider opinions that large percentages of their caseloads are in need of these services, while a smaller percentage of consumers identify these needs. Although housing ranked as the highest provider-identified gap and was ranked 2nd by consumers, 58% of providers noted that this was a gap for their clients as opposed to 24% of consumers. It is important to note that providers were more likely to prioritize the component service “help finding housing” as significantly more of a gap than consumers (39% versus 19%), perhaps related to the fact that currently homeless consumers may not have had access to the survey.

Consumers were significantly more likely than providers to identify gaps in food and meal programs (13% versus 5%), legal services (18% versus 11%) and phone referral services to medical and dental care (10% versus 2%).

G. Comparison of Service Priorities and Service Gaps

Consumer-identified service priorities as compared to service gaps: Comparing service gaps with service priorities helps determine the magnitude of potential system inadequacies and supports strategic planning and resource allocation decisions. Table 18 lists the top ten consumer-identified service priorities in comparison with the gap ranking and percentage for each service. Seven of the top ten consumer priorities also ranked among the top ten gaps.

Consistent with results from previous years, the service that consumers reported as having the highest priority-to-gap ratio was emergency financial assistance (48% of consumers rating the service as a priority and 34% identifying it as a gap). As noted previously, the very low income levels exhibited by a high percentage of consumers may be responsible for the high importance placed on this service, as well as consumer sentiments that current emergency grant programs are not able to keep pace with their needs.

**Table 18. Service Priorities as Compared to Service Gaps
from Consumer Surveys**

Service	PRIORITY (n=467)		GAP (n=483)	
	Rank	% of Resp.	Rank	% of Resp.
Ambulatory/outpatient medical care	1	66%	22	2%
Oral health care	2	61%	6	17%
AIDS Drug Assistance Program	3	59%	12	8%
Case management	4	57%	16	6%
Housing assistance/related services	5	50%	2	24%
Emergency financial assistance	6	48%	1	34%
Health insurance	7	41%	14	7%
Food bank/home-delivered meals	8	33%	9	13%
Psychosocial support	9	32%	3	21%
Mental health services	10 (tie)	30%	8	14%

Outpatient medical care and case management (identified among the top service priorities across almost all sub-populations of PLWH) were rarely identified as gaps. Only 2% of consumers reported that they needed, but could not obtain outpatient medical care, and only 6% identified case management as a service gap.

H. Unmet Need for Medical Care

In recent years, the Health Resources and Services Administration (HRSA) has placed increased emphasis on the need to identify individuals who know their HIV status but are not receiving HIV-related medical care. This was the basis for several CARE Act amendments in 2000, aimed at getting PLWH into care as soon as possible after their HIV diagnosis and ensuring retention in HIV-related primary care.

The Seattle EMA has used several data sources to determine the extent of unmet medical care needs in King County. The first source is information gleaned from the 2003 Comprehensive Needs Assessment. The second is a collaborative Titles I and II quantitative data project that calculated the overall number of persons in Washington State, King County and the Seattle EMA

who do not meet the standardized definition of being in primary medical care.

Information from the 2003 Needs Assessment: The survey asked respondents if they used medical care, did not need or want medical care, or needed but could not get medical care. Of the 444 valid responses to this question, 94% of survey respondents reported current use of ambulatory medical care. This figure is identical to responses from both the 1999 and 2001 surveys.

Two percent of survey respondents (9 out of 444) reported that they needed, but could not get medical care. Of these, all nine were able to identify their last T-cell and viral load counts, five were currently taking antiviral medications and two reported taking protease inhibitors. This suggests that several of these individuals may actually be receiving medical care.

An additional 5% of respondents (n=20) identified outpatient medical care as a service that they did not need. Of these twenty individuals, all but two knew their latest T-cell count and all but one knew their viral load. Five of the twenty reported viral loads over 500 and eight reported undetectable viral loads. Half of the PLWH who reported not needing medical care were currently taking some form of antiviral medications and/or protease inhibitors. This suggests that these consumers have had at least some contact with medical professionals regarding their HIV disease, although they may not consider themselves to be currently using the service.

No statistically significant differences emerged regarding utilization of medical care based on demographic factors. However, PLWH who reported having been incarcerated in the past year were somewhat less likely than other PLWH to be using medical care (84% versus 94%). Women were somewhat less likely than men to report utilization of primary medical care during the past year (90% versus 94%), although neither of these findings are statistically significant.

The percent of providers who noted a gap in their clients' access to primary care dropped by 50% from 2001 to 2003 (10% in 2001; 5% in 2003). Key informant interviews revealed that the gap is not actually due to lack of available slots for medical care. As in past years, providers noted that the gap was related to clients with mental illness and substance use histories (for whom these co-morbidities often serve as barriers to maintaining medical care) and the emerging population of refugee PLWH without legal standing. For these individuals, cultural norms against seeking medical care until one is very sick (or lack of trust in the Western medical system) was the major barrier that prevented clients from obtaining the level of care their providers believed they need.

Quantitative unmet need analyses: In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened a workgroup across Titles I and II, comprised of grantee staff, health planners and epidemiologists from Public Health and the Washington State Department of Health. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

The unmet need calculation process steps included:

- reviewing and revising methods for estimating HIV prevalence;
- choosing data sources and calculating preliminary estimates;
- reviewing preliminary results and adjusting for bias or missing source data.

At its first meeting, the workgroup agreed to adopt the UCSF definition of “in care”: evidence of a CD4 count, viral load test or administration of HAART therapy within the previous 12 month period. Persons determined to be “not in care” were those for whom no evidence existed of any of these three clinical markers during the prior year.

Primary data for estimating prevalence was available from the HIV/AIDS Reporting System (HARS). As of 11/02, AIDS reporting in Washington State was evaluated to be 95% complete, with HIV reporting – first implemented in September of 1999 – to be 75% complete. Lab reporting records on CD4 and viral load tests was estimated to over 95% complete. This was chosen as the primary source of data because the data were readily available, representative of all providers of HIV care (both public and private), and directly matched with surveillance records. Because it is highly unlikely that any PLWH would be prescribed ongoing HAART therapy without evidence of recent CD4 and/or viral load tests, the Workgroup decided that laboratory reports on either of these tests within the prior 12 month period would serve as the marker of “in care.”

An adjustment was made on all preliminary data to address the fact that laboratory reporting in Washington State excludes CD4 counts above 200 and undetectable viral loads. Data from the Adult Spectrum of Disease (ASD) study demonstrate that 27.6% of patients in 2000 and 2001 had only non-reportable lab results. As a result, data on care patterns was adjusted to account for patients with non-reportable lab results.

Based on these analyses, it is estimated that 76.1% of King County PLWH who are HIV+ and aware of their serostatus are in care and 23.9% of PLWH meet the UCSF definition of being “not in care.” The “not in care” estimate represents 1,409 PLWH (95% confidence interval: low estimate of 1,336; high estimate of 1,484). (Table 19)

Sub-population analysis was conducted based on sex, race/ethnicity and HIV/AIDS status. Data regarding age, mode of transmission and other demographic indicators was less easily abstracted from lab reports, HARS and ASD data. The workgroup intends to devise methods to incorporate these additional analyses in upcoming “not in care” estimates. The Workgroup intends on meeting annually to review and revise these “not in care” estimates, for both state and local use during all prioritization, allocation and planning processes.

**Table 19. Unmet Need for Primary Care in King County
(Based on Reported HIV/AIDS Cases Not Known to be Deceased
as of 1/01/2001)**

HIV+ Population	% with Met Need	Estimate of Unmet Need	95% Confidence Range	
			Lower	Upper
HIV, non-AIDS	74.3%	730	678	785
AIDS	77.4%	691	640	744
Male	75.3%	1,320	1,249	1,393
Female	83.7%	89	71	109
White	76.6%	1,017	955	1,081
Black	76.8%	200	173	229
Hispanic	71.8%	131	109	155
Asian/PI	67.2%	42	30	56
Native American	84.3%	15	8	24
Unknown Race	53.8%	6	2	13
TOTAL*	76.1%	1,409	1,336	1,484

*May not add to 100% due to rounding.

V. Specific Population Findings

Data on specific sub-populations of persons living with HIV/AIDS are drawn from several sources. Epidemiologic data and summaries are excerpted from HIV/AIDS Epidemiology Profile for Community Planning 2003, published by the HIV/AIDS Epidemiology Unit of Public Health – Seattle & King County. All other information is derived from data from the 2003 consumer surveys, provider interviews, and focus groups, except where noted. (See Section III, Methods) Italicized quotes have been excerpted from consumer focus group transcripts, provider interviews and narrative sections of the consumer and provider surveys.

Within each sub-population, reports are organized as follows:

- 1. Epidemiologic Profile:** A summary of the population-specific data regarding AIDS case status and trends, population size, seroprevalence estimates and subgroup highlights (where appropriate).
- 2. Service Trends:** Patterns in overall service utilization, including demographic trends and population-specific needs as identified by consumers and providers.
- 3. Service Priorities:** Services that have been identified as priorities for the target population, by consumers themselves and/or by providers with expertise and experience in working with the population. The top ten priorities per sub-population from the consumer survey are listed.
- 4. Service Gaps:** Services that consumers and/or providers have identified as deficient, either because the service is not available, not accessible, or is not delivered in a manner consistent with sub-population needs. The top ten service gaps per sub-population from the consumer survey are listed.
- 5. Unmet Need for Medical Care:** Quantitative estimates of the number of PLWH in the sub-population who do not meet the definition of being “in medical care”, and factors identified by consumers and providers which serve as barriers to utilization of medical care. The definition of “in care” is consistent with the HRSA/UCSF definition of “in care” as evidenced by a CD4 count, viral load test or administration of HAART therapy within the previous twelve-month period. PLWH determined to be “not in care” were those for whom no evidence existed of any of these three clinical markers during the prior year.

(NOTE: All results noted as statistically significant were tested at the $p < .05$ level.)

A. Men who have Sex with Men

“It seems that services for those of us that use them seem to becoming harder to get. I’m grateful for what I get, but I fear for others who are less fortunate.” (African American MSM PLWH)

1. Epidemiologic Profile

Men who have sex with men (MSM) were the earliest group affected by HIV/AIDS in King County and continue to bear the largest burden of HIV infections and AIDS diagnoses. In King County, 85% of persons living with HIV/AIDS of known risk are MSM, including MSM who have injected drugs (MSM/IDU). (NOTE: Where appropriate, information on MSM/IDU will be discussed in both this section and Section B, “Injection Drug Users.”)

Population sizes: Based on data from a variety of sources, Public Health – Seattle & King County estimates that MSM number between 32,000 and 53,000 in King County, including approximately 2,500-3,800 MSM with histories of injection drug use. There are an estimated 6,300 HIV infected MSM without an IDU history, and an estimated 800 HIV infections county-wide with any history of injection drug use as a reported risk. As of 12/31/2002, 3,584 MSM and 465 MSM/IDU were reported to Public Health and presumed living with HIV or AIDS in King County.

Status and trends in HIV/AIDS cases: Although MSM are still the largest subgroup with AIDS in King County, AIDS case report data show a declining trend in annual HIV diagnoses among MSM beginning in 1994. The proportion of new HIV cases among MSM not injecting drugs decreased from 78% of those with known risk in 1993-95 to 69% in 2000-2002. Non-IDU MSM also dropped from 79% to 69% of AIDS diagnoses in the same time periods. The proportion of HIV diagnoses among MSM/IDU has remained roughly level at 8-9% of all diagnoses with known risk from 1994-2002. The percent of AIDS cases in MSM/IDU was level at 10% for the same time period.

HIV seroprevalence: Assuming the population of MSM without injection drug history is correct, between 13% and 21% of all MSM in King County are infected with HIV. The infection rate is greater among MSM/IDU (between 21% and 32% of MSM/IDU being HIV-infected).

Among MSM, the highest levels of HIV prevalence were generally found in:

- older MSM compared to younger MSM
- MSM with histories of STD’s
- MSM/IDU, especially methamphetamine injectors, relative to those with no IDU history
- African-American MSM relative to Whites and others
- men who had sex exclusively with other men rather than both men and women.

Subgroup highlights:

MSM of color: Among men of color currently living with HIV/AIDS, 68% reported male-male sex with or without IDU as a risk factor for HIV. This proportion is lower than among White male PLWH (93% reporting male-male sex). Of male HIV/AIDS cases reported through 2002,

58% of African Americans were MSM or MSM/IDU, compared to 78% of Latinos, 82% of Native Americans, and 80% of Asians/Pacific Islanders.

MSM Injection Drug Users (MSM/IDU): Amphetamine use was reported by 40% of MSM drug injectors, in comparison to 4% of non-MSM drug injectors in unlinked seroprevalence studies at King County drug treatment centers from 1988 through 1997. In an interview study of IDUs conducted in King County from 6/94-5/98, amphetamine was the common injection drug for 33% of MSM injectors compared to 5% of all other injectors. In this same study, the seroprevalence of HIV was 47% in MSM whose primary injection drug was methamphetamine, compared to 14% of MSM who primarily injected other drugs.

2. Service Trends

As in previous years, providers of services to MSM report that the large majority of their clients are White (ranging from 70%-80%, depending on the provider). Providers reported a continued increase in gay men of color, mostly among Hispanic MSM. Providers also noted that they are seeing a rise in younger MSM clients, especially those in their 20's. They reported an increase in newly diagnosed MSM clients over the age of 40, as well as seeing an aging client caseload of MSM PLWH aged 50 and over.

Most of the White MSM clients are residents of Seattle. MSM of color are more likely to reside in South King County, particularly Latino MSM. Providers also reported a significant increase in the percentage of clients who have experienced homelessness, across all races and ethnicities.

As first identified in 1997, providers continue to see high percentages of MSM clients presenting with mental illness and chemical dependency. In particular, providers noted an increasing incidence of severe clinical depression in their MSM clients. Providers noted that a higher percentage of these clients are now taking antidepressants and/or self-medicating. An increasing percentage is also presenting with more severe mental health diagnoses, such as bipolar disease and personality disorders. On the 2003 consumer survey, 59% of White MSM respondents and 40% of MSM of color reported having been diagnosed with a mental illness.

Providers report that a substantial percentage of their MSM clients are current or former substance users, although the number has leveled in the past several years. "Drugs of choice" for these MSM clients appear to be broken down along racial lines. For White MSM, crystal methamphetamine continues to be the main non-injection drug of choice. Almost twice as many White MSM survey respondents reported meth use as did MSM of color (16% versus 9%). For these individuals, meth use is often coupled with Ecstasy. Among African American MSM PLWH, crack cocaine use is more common (14% of MSM of color reporting cocaine use versus 9% of White MSM). Providers whose caseload is primarily composed of MSM/IDU report high levels of multi-drug use among their clients. Alcohol abuse is also reported as being widespread.

2003 consumer survey data reveal several differences in HIV-related health status between MSM of color and White MSM. MSM of color were significantly more likely than White MSM to report themselves as being HIV+ but not AIDS-disabled (38% versus 29%). Overall, MSM of

color were less likely than White MSM to be taking all forms of HIV medications: antiretrovirals (69% versus 77%), protease inhibitors (43% versus 49%) and medications to treat and prevent opportunistic infections (30% versus 41%). Despite these disparities, the percentage of MSM of color who reported taking one or more forms of HIV-related medications has risen in each succeeding survey year.

Providers of services to MSM noted that access to HIV medications was rarely an issue and/or barrier for their clients. Medical providers noted that compliance with HAART has generally improved during the past several years. However, MSM/IDU clients are more likely to experience adherence challenges than MSM without injection drug use histories. Providers noted that compliance is also a problem with MSM clients in situations where confidentiality is still an issue, such as non-self identified MSM of color in family situations or MSM who are still working but are not “out” about their HIV status in their place of employment.

As in past years, MSM continue to report high utilization of clinical and support services. Continuing a trend first observed in 2001, white MSM exhibited service utilization rates that were lower than MSM of color in most service categories. Of particular note is that White MSM were less likely than MSM of color to report utilization of financial assistance programs, such as grocery vouchers (25% versus 47%), help paying rent (38% versus 52%) and help paying for utilities (29% versus 42%). MSM of color were also more likely to use peer or client advocacy programs than White MSM (41% versus 26%).

3. Service Priorities

MSM survey respondents ranked primary medical care as their highest service priority, followed by dental care, the AIDS Drug Assistance Program, case management, and housing assistance or housing-related services (Table 20).

Table 20. Service Priorities: MSM (n=357; 5 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Ambulatory/outpatient medical care	245	69%
2	Oral health care	226	63%
3	AIDS Drug Assistance Program	221	62%
4	Case management	206	58%
5	Housing assistance/related services	172	48%
6	Emergency financial assistance	160	45%
7	Health insurance	158	44%
8	Food bank/home-delivered meals	123	34%
9	Mental health services	114	32%
10	Psychosocial support	105	29%

Very few significant differences emerged in the ways in which White MSM and MSM of color prioritized services. This is a marked change from 2001 survey responses. White MSM were significantly more likely than MSM of color to prioritize mental health services (36% versus 21%), while MSM of color were more likely than White MSM to prioritize housing services (45% versus 55%).

4. Service Gaps

As with most other populations, MSM PLWH identified emergency financial assistance as the highest service gap. Other highly ranked service gaps for this population include housing services, psychosocial support, alternative therapies, legal assistance and oral health care (Table 21). Within the housing category, a larger gap emerged in help paying rent (20%) than in help finding housing (12%). In the psychosocial support category, one-on-one peer support (17%) was identified as the highest gap, as opposed to support groups or spiritual counseling (both at 8%). Grocery vouchers were rated as a slightly higher emergency financial assistance gap (27%) than was help paying for utilities (22%).

Table 21. Service Gaps: MSM (n=362)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	127	35%
2	Housing assistance/related services	84	23%
3	Psychosocial support	81	22%
4	Alternative/non-Western therapies	72	20%
5	Legal services	66	18%
6	Oral health care	65	18%
7	Client advocacy	52	14%
8	Mental health services	47	13%
9	Food bank/home-delivered meals	40	11%
10	Referral for health care services	35	10%

MSM were not statistically more likely than other PLWH to identify service gaps in any category. The only category in which an MSM sub-population was more likely to identify gaps was in health education/risk reduction, in which MSM of color were more likely than non-MSM to note lack of access to this service (9% versus 4%).

Data from the 2003 survey were also used to quantify the unmet needs of MSM. This was accomplished by applying the percent of MSM identifying service gaps across the population estimate of 4,049 MSM and MSM/IDU reported to Public Health and presumed living with HIV or AIDS in King County. Analysis indicates that the greatest unmet need for this population exists in the area of emergency financial assistance, with approximately 1,420 MSM being unable to obtain utility and/or grocery voucher assistance. An additional 930 MSM display unmet needs for housing assistance, with the majority of this need being rental assistance. These numbers reflect the increasing percentage of long-term survivors in this population who

are now living on fixed incomes below 200% of FPL (Federal Poverty Level). Approximately 890 MSM have unmet needs for peer counseling, particularly African-American and Latino MSM.

Providers reported that housing continues to be a significant challenge for their MSM clients. This is particularly true for MSM clients who are HIV+, but not AIDS disabled and for clients with histories of incarceration or active substance use issues. The majority of MSM focus group participants (White MSM: n=9; MSM of color: n=7) were in stable housing situations, although many of them expressed concerns about their ability to keep pace with rising rental costs.

Providers noted an overall increase among MSM clients who are seeking more help with financial assistance and insurance income benefits. Growing numbers of MSM clients are entering the system with no income and/or no insurance. Providers reported service gaps for their MSM clients (and clients in general) in accessing Medicaid dental care due to a severe shortage of providers who are willing to accept this form of reimbursement. Additionally, providers noted that coverage for complex procedures such as bridges, crowns and dentures is relatively impossible to secure for their clients. Consumers expressed frustration in navigating the dental care system, reporting extensive delays in accessing even basic dental care. Based on reports from providers, emergency dental appointments are also hard to secure.

5. Unmet Need for Medical Care

“My case manager and my financial advocate have been my saviors. After being hospitalized three times this year for AIDS-related illnesses, without their assistance I would be homeless and without insurance to receive the medical care and medications that keep me alive.” (White MSM PLWH)

Ninety-four percent of both White MSM and MSM of color survey respondents reported current utilization of primary care services. Lack of access to primary care was reported by only 2% of MSM survey respondents. However, MSM living outside of Seattle reported having to travel long distances to obtain medical services. Neither consumers nor providers of services to this population reported barriers to accessing HIV/AIDS medications, although providers noted that adherence to with complex dosing regimens remain problematic for many of their clients, and that treatment failures continue, particularly for long-time survivors.

Providers noted that cultural differences may exist for some immigrant MSM of color (particularly Latinos and Asian/Pacific Islanders) regarding utilization of primary care. For some members of these populations, there may be a lack of trust in Western medical care or a cultural norm against seeking medical care unless debilitating clinical illness exists. MSM of color who participated in the “Care Project 2002” consumer interview project were almost twice as likely as White MSM to report having had problems in accessing medical care (8.5% versus 4.3%). The primary reasons given for these problems included a lack of providers of color in the system, language barriers (particularly for monolingual Spanish-speakers) and lack of attention to cultural issues on the part of some service providers.

Access to prescription drugs did not emerge as a significant problem for MSM, but providers noted that medication adherence for MSM of color (particularly Latinos and Asians/ Pacific Islanders) can be complicated by language barriers, cultural norms about taking medications, and lack of trust in Western medicine. Nevertheless, 78% of MSM of color survey respondents reported using Washington State's AIDS Drug Assistance Program, a rate 12% higher than for White MSM. The percentage of MSM of color who reported utilizing primary care and ADAP has increased steadily with each successive round of consumer surveys.

Although the Seattle EMA has completed its initial process of calculating unmet need using the University of California, San Francisco (UCSF) Unmet Need Framework, sub-population analysis to date has been limited to demographics based on sex, race/ethnicity and HIV/AIDS status. As a result, it is not possible at this time to use the UCSF model to quantify unmet primary care need for MSM, because data based on transmission risk is not available.

At present, quantitative estimates of MSM (including MSM/IDU) who have an unmet need for primary medical care are based on two assumptions: (1) an estimated number of 3,296 White MSM and 751 MSM of color reported to Public Health and presumed living with HIV or AIDS in King County and (2) the percent of 2003 MSM consumer survey respondents who either reported not receiving primary care, not having a T-cell count in the past year, or not having a viral load count in the past year. The percent of White MSM and MSM of color PLWH on the consumer survey meeting the "not in care" definition was applied against the overall number of PLWH in this sub-population in King County to develop an overall not-in-care estimate. Using this model, an estimated 425 White MSM PLWH are not in care (12.9% of the total White MSM PLWH population of 3,296) and 197 MSM of color PLWH are not in care (26.3% of the total MSM of color PLWH population of 751). The percentage of MSM of color who are not in primary care is double that of White MSM, suggesting that improved outreach to this population and linkage into the primary care system continues to be an ongoing issue.

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project include information about persons who received a "late diagnosis" with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that 66 out of 365 (18.1%) of White MSM and 79 out of 234 (33.8%) MSM of color PLWH who received an AIDS diagnosis during the period from 1996-2001 received a "late diagnosis" of HIV. In 2001, the last complete ASD reporting year, the percentage of late diagnoses in MSM of color was 42.3%, supporting the "not in care" data that suggest that increased efforts to refer and enroll MSM of color PLWH into primary care are necessary.

MSM focus group participants were all currently enrolled in primary medical care, and all had been to see their providers within the past six months. None reported major barriers to accessing medical care within the past five years, either for themselves or for their peers. However, several MSM participants noted that they had friends who they believed were at high risk for HIV but refused to be tested due to fear of learning the results.

B. Injection Drug Users

“There are probably many drug users living with HIV on the streets who are not connected to services and don’t even know services are available. Most of them are in denial. They only learn that they are HIV positive when they get sick.” (Substance use counselor)

1. Epidemiologic Profile

As in other cities in the Western United States, the number of cases of HIV and AIDS among drug injectors in King County is far lower than among gay and bisexual men. However, the percent of AIDS cases attributable to injection drug use (IDU) in King County has increased from 4% in 1982-1987 to 7% in 2000-2002.

Population sizes: There are an estimated 150,000 people in King County at increased risk of HIV infection because of illicit drug or alcohol abuse. About 15,000 of these are at increased risk due to drug injection practices.

Based on estimates from reported cases, up to 620 HIV-infected heterosexual IDU reside in King County. The estimated number of HIV-infected men who have sex with men and who also currently inject drugs is 800. Most of these men are thought to have acquired HIV through sexual transmission rather than by sharing of injection equipment. As of 12/31/2002, 344 heterosexual IDU and 465 MSM/IDU were reported to Public Health and presumed living with HIV or AIDS in King County.

Status and trends in HIV/AIDS cases: The first AIDS case among King County IDU males and females were reported in 1986. The proportion of cases attributed to drug injection among heterosexuals has increased from about 4% of cases in 1982-1987 to 7% in 2000-2002. While the number of male IDU (235) in King County reported living with HIV/AIDS is higher than the number of female IDU (109), the proportion of male cases whose infection was attributed to IDU is 5% versus 23% among females.

Injection drug use is a relatively more common route of HIV transmission for King County African Americans with HIV/AIDS (15% of living cases), Latinos/Latinas (9%) and Native Americans/Alaska Natives (27%) compared to Whites or Asian/Pacific Islanders (4% each).

HIV seroprevalence: There are approximately 620 HIV infections among the estimated 15,000 IDU residing in King County, which suggests that about 4% of all IDU are HIV-infected. In unlinked surveys conducted by Public Health, 1.5% of over 7,000 IDU entering King County drug treatment programs between 1988-1999 tested HIV positive. HIV prevalence did not change significantly over this time period.

IDU in treatment (such as those tested in the unlinked surveys) tend to be at lower risk of HIV than other injectors. In one study, HIV prevalence among IDUs recruited at the King County Jail and at needle exchange sites was more than twice as high as IDUs in treatment.

2. Service Trends

According to information from providers of services to injection drug using PLWH, the overall demographics of the population have changed in the past two years. The population of IDU PLWH is still primarily male (approximately 60% of clients served), although providers are seeing a substantial increase in the number of HIV+ female IDU. Approximately two-thirds of the male clients are White, with the rest almost equally divided between African-Americans and Latinos. Providers noted that their female IDU PLWH caseloads are equally divided among Whites and persons of color, primarily African American women and rising numbers of Native Americans. IDU respondents to the consumer survey were more likely to be persons of color than non-IDUs (49% versus 40%). Providers also noted that most of their clients are in the 35-45 age range, with increasing numbers of younger women seeking services shortly after being diagnosed with HIV.

Homelessness is also a major, and growing, problem in this population. Providers of chemical dependency services report that many of their IDU PLWH clients are homeless upon intake, and approximately 10% of their female IDU and between 25-50% of male IDU are currently or recently homeless. Survey respondents with substance use histories were also more likely as non-IDU PLWH to have been homeless in the past year (37% versus 26%).

Providers noted that well over half of their IDU clients have been in jail or prison, mostly for drug-related offenses. In many cases, incarceration is chronic, with clients returning to jail for repeat offenses. Consumer survey data support this statement, as IDU PLWH were significantly more likely than other consumers to have been incarcerated in the past year (16% versus 2%).

As noted in previous years, providers are seeing high rates of multi-drug use (both injectable and non-injectable) among their IDU clients, including rising rates of alcohol abuse. A major development in recent years is the growing number of women using crystal methamphetamine, a drug previously reported almost exclusively among White MSM. Among IDU respondents to the consumer survey, 34% reported using methamphetamine, 28% used cocaine, 15% used poppers or inhalants, and 13% used downers. Thirty-four percent of IDU also reported alcohol problems in the past year.

The number and percent of IDU PLWH who reported using substance use treatment has also risen during each of the past three rounds of surveys. In 1999, 32% of IDU survey respondents reported using substance use counseling services. In 2001, this figure rose to 42%. This year, 51% of IDU PLWH survey respondents reported using substance use treatment. These increasing figures are consistent with utilization reports from service providers, suggesting that case managers are becoming more effective in linking their clients to treatment assessments, enrolling them in one-on-one or group counseling, and entering them into methadone maintenance programs.

Providers continue to report seeing increasing percentages of their IDU PLWH clients who are both chemically dependent and mentally ill. Clinical depression and untreated bipolar disorder are very common in the IDU PLWH population. Crystal meth-induced paranoia is also relatively common. IDU survey respondents were significantly more likely than other PLWH to

report having been diagnosed with a mental illness (79% versus 48%). The percent of IDU survey respondents who reported mental illness has increased by 27% in the past two years.

Providers note that their MSM/IDU clients are generally seeking HIV-related medical care treatment earlier in their HIV disease than in recent years. The converse is true of heterosexual male IDU, who are entering care later in their HIV disease and experiencing higher morbidity levels. These men are also presenting with a higher rate of co-infections with Hepatitis B and C, cancers and other liver problems. Female IDU are also entering care later in their disease, particularly those who have not previously sought substance abuse treatment services.

3. Service Priorities

Injection drug using PLWH identified case management services as their highest service priority in 2003, followed by housing services, primary medical care, emergency financial assistance and oral health care (Table 22).

IDU PLWH were significantly more likely to identify several services as priorities compared to non-IDU consumers. Chief among these is case management, identified as a service priority by 67% of IDU versus 55% of non-IDU consumers. IDU consumers were also more likely to prioritize food and meal programs (43% versus 31%) and adult day health programs (18% versus 9%). Not surprisingly, IDU were five times more likely to prioritize substance use treatment, including non-injection treatment (25% versus 5%).

**Table 22. Service Priorities: Injection Drug Users
(n=87; 8 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Case management	58	67%
2	Housing assistance/related services	51	59%
3	Ambulatory/outpatient medical care	50	57%
4	Emergency financial assistance	46	53%
5	Oral health care	44	51%
6	AIDS Drug Assistance Program	43	49%
7	Food bank/home-delivered meals	37	43%
8	Psychosocial support	27	31%
9	Mental health services	26	30%
10	Substance abuse services	22	25%

5. Service Gaps

Injection drug using PLWH identified service gaps that were relatively similar to those reported by other populations. The number one service gap identified by injection drug using consumers

was emergency financial assistance, followed by housing assistance, psychosocial support, mental health services and substance abuse services (Table 23).

IDU survey respondents were less likely than other consumers to report unmet service needs. The only service that was significantly more likely to be seen as a gap by IDU was substance use treatment (13% versus 2%). This is consistent with the percentage of IDU survey respondents in 2001 who reported this gap.

Table 23. Service Gaps: Injection Drug Users (n=95)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	18	28%
2	Housing assistance/related services	11	17%
3	Psychosocial support	10	15%
4	Legal services	9	14%
5 (tie)	Mental health services	9	14%
5 (tie)	Substance abuse services	8	12%
7 (tie)	Referral for health care services	8	12%
7 (tie)	Alternative, non-Western therapies	7	11%
9 (tie)	Oral health care	7	11%
9 (tie)	Client advocacy	6	9%

Data from the survey were also used to quantify the unmet needs of IDU PLWH. This was accomplished by applying the percent of IDU (including MSM/IDU) identifying service gaps across the population estimate of 809 IDU reported to Public Health and presumed living with HIV or AIDS in King County. Analysis indicates that approximately 230 IDU PLWH in the Seattle EMA have an unmet need for emergency financial assistance; 140 have an unmet need for housing assistance (in particular, help paying rent); 120 have an unmet need for psychosocial support; and 110 have an unmet need for legal services and mental health services, respectively.

Providers of service to injection drug using PLWH frequently mentioned housing as the main service that their clients were unable to access. Providers noted a lack of affordable housing in general for low income persons in King County, particularly for their clients who are living at or below 100% of poverty level. The combination of active substance use and histories of incarceration often prove to be insurmountable barriers to successful housing, in many cases making clients ineligible for most forms of permanent housing.

5. Unmet Need for Medical Care

“When I stopped taking my meds and being compliant, my medical providers became not as responsive to me. When I became more engaged, they responded better. The harder I work at it, the better they work with me.” (Former IDU PLWH)

Data from the 2003 consumer survey reveal several differences between HIV-related health care status between IDU PLWH and non-IDU PLWH. Although IDU were slightly more likely than other consumers to be disabled by AIDS, IDU consumers were significantly more likely than non-IDU to be unaware of their T-cell counts (16% versus 9%) and viral loads (19% versus 11%). IDU respondents were also three times more likely than other consumers to report viral loads over 100,000 (12% versus 4%).

Significant differences emerged between IDU and non-IDU PLWH regarding the types of HIV-related medications they were taking. IDU were significantly less likely to report taking antiviral medications (63% versus 80%), protease inhibitors (37% versus 53%) and medications to manage HIV-related side effects (32% versus 42%). Although providers reported no actual difficulties for their IDU clients in accessing prescription medications, they did note significant adherence challenges in this population. Barriers to medication adherence include lack of housing and ongoing substance use. Several focus group participants (n=6) also noted that they were unwilling to continue their medication regimens due to problems with side effects.

Although the Seattle EMA has completed its initial process of calculating unmet need using the UCSF Unmet Need Framework, sub-population analysis to date has been limited to demographics based on sex, race/ethnicity and HIV/AIDS status. As a result, it is not possible at this time use the UCSF model to quantify unmet primary care need based on IDU status, because data based on transmission risk is not available.

At present, quantitative estimates of IDU (including MSM/IDU) who have an unmet need for primary medical care are based on two assumptions: (1) an estimated number of 809 IDU reported to Public Health and presumed living with HIV or AIDS in King County and (2) the percent of 2003 IDU consumer survey respondents who either reported not receiving primary care, not having a T-cell count in the past year, or not having a viral load count in the past year. The percent of IDU PLWH on the consumer survey meeting the “not in care” definition was applied against the overall number of PLWH in this sub-population in King County to develop an overall not-in-care estimate. Using this model, it is estimated that 188 IDU PLWH are not in care (23.2% of the total IDU PLWH population of 809). This estimate may be low, due to potential sampling bias on the consumer survey and the probability that lower percentages of respondents acknowledged substance use histories than is actually the case. It should be noted, however, the IDU participants in the 2002 consumer interview project reported rates of CD4 testing, viral load testing and HAART therapy that were equally as high as non-IDU respondents.

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project include information about persons who received a “late diagnosis” with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that 55 out of 197 (27.9%) IDU PLWH who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 41.7%, suggesting that increased efforts to refer and enroll IDU PLWH into primary care are necessary.

Consumer focus group and provider interview data suggest that both heterosexual and MSM IDU displayed a lack of trust in the medical establishment and in HIV treatments, as well as concerns about being judged by care providers about their substance use. IDU PLWH may perceive that they receive a lower standard of care from medical providers due to their substance use. Lack of access to medical care did not emerge as a significant barrier for either group.

C. People of Color

(NOTE: Information is reported by specific sub-populations of communities of color, based on data from consumer surveys and focus groups and provider surveys and key informant interviews. Data tables include aggregate statistics from consumer survey respondents who identified as African American (n=59), Latino/Latina (n=56) or Asian/Pacific Islander (n=21). The number of Native Americans/Alaska Natives (n=10) and Africans (n=11) who responded to the survey is insufficient from which to develop useful data tables for these populations or on which to run tests for statistical significance. As a result, information presented regarding PLWH from these populations is based primarily on key informant provider interviews and focus group responses.)

“The more outreach provided to minority communities regarding HIV/AIDS services, the better. Reaching the medical providers who serve these communities is equally important to assure that every doctor who has a patient who tests positive knows where to refer that patient for services and support.” (Case manager)

1. Epidemiologic Profile

In Seattle-King County, as in the United States as a whole, epidemiologic data indicate that HIV and AIDS have disproportionately affected African Americans, Native Americans/Alaska Natives, and persons of Hispanic ethnicity compared to Whites or Asian/Pacific Islanders. The racial disparity is even greater among women of color compared to men of color.

Status and trends in AIDS cases, with population sizes: Of the total of 8,400 estimated King County residents currently living with HIV infection (including those with AIDS), an estimated 2,250 (27%) are people of color. By race/ethnicity, the estimated number of HIV-infected persons includes approximately 6,150 (73%) non-Hispanic Whites, 1,240 (15%) African Americans, 690 (8%) persons of Hispanic ethnicity, 180 (2%) Asians/Pacific Islanders and 140 (2%) Native Americans/Alaska Natives. As of 12/31/2002, 770 African Americans, 412 non-Hispanic Whites, 108 Asians/Pacific Islanders and 84 Native Americans/Alaska Natives were reported to Public Health and presumed living with HIV or AIDS in King County.

The percent of newly-diagnosed HIV/AIDS cases among people of color has risen steadily since the early years of the epidemic in King County, increasing from 12% of cases in 1982-1987 to 27% in 1994-1996 and to 38% in 2000-2002. This trend has been most evident among African American and Hispanic persons. Population based HIV rates from 2000-2002 demonstrate the epidemic's disproportionate impact on persons of color, with rates among African Americans, Latino/as and Native American/Alaska Natives being two to five times that of Whites in King County. HIV/AIDS rates among Asian/Pacific Islanders, however, continue to be significantly lower than Whites (Table 24).

Racial disparities are greatest among African American women compared to women of other races/ethnicities. In 2000-2002, the average annual rate of HIV/AIDS for African American females (446 per 100,000) in King County was 13 times greater than that of White females (30 per 100,000). Rates among Native Americans/Alaska Natives (307 per 100,000) and Latinas (83

per 100,000) were also substantially higher than the rates for White women, but these rates must be interpreted with caution due to the small case numbers among Native American and Latina women.

Table 24. Comparison of King County Racial Composition with New HIV Diagnoses (2000-2002)

	King County (est. 2000 pop.)	(% of pop.)	HIV/AIDS cases (2000-2002)	(% of cases)	AIDS case rate per 1000,000 population
White	1,309,130	(75%)	651	(62%)	16.6
African American	105,205	(6%)	234	(22%)	74.1
Latino/Latina	95,242	(6%)	110	(11%)	38.5
Asian/Pacific. Islander	210,156	(12%)	31	(3%)	4.9
Nat. Amer./AK Native	17,311	(1%)	12	(1%)	23.1
TOTAL	1,737,034	(100%)	1,043	(100%)	20.0

More African American and Native American/Alaska Native men and women acquire HIV from injection drug use as compared to other groups. The percent of AIDS cases by race for selected HIV exposure categories for males and females are given in Table 25.

Table 25. AIDS Cases by Race and Selected HIV Exposure Categories (6/02)

MALES (N=4,648)	White	Afr-Am	Latino/a	A/PI	NA/AN
MSM non-injectors	82%	51%	72%	76%	50%
MSM drug injectors	11%	7%	6%	4%	32%
Heterosexual drug injectors	3%	13%	10%	4%	15%
Heterosexual non-injectors	1%	13%	3%	3%	2%
Undetermined/not reported	2%	16%	9%	13%	2%
FEMALES (N=454)	White	Afr-Am	Latino/a	A/PI	NA/AN
Drug injectors	28%	20%	6%	0%	64%
Heterosexual non-IDU	47%	45%	58%	38%	18%
Heterosexual non-injectors	2%	4%	3%	8%	0%
Perinatal exposure	3%	4%	6%	8%	0%
Undetermined/not reported	20%	27%	28%	46%	18%

HIV seroprevalence: Seroprevalence data from unlinked surveys from the Harborview Sexually-Transmitted Disease (STD) Clinic indicate higher rates of HIV among heterosexual African American and Hispanic men and women compared to Whites. In Clinic surveys conducted in 2000-01, 0.2% of heterosexual Whites (n=1,504) tested HIV positive, compared to 0.7% of African Americans (n=562) and 0.7% of Hispanics (n=146). No heterosexual Asians/Pacific Islanders (n=746) since 1990 or Native Americans/Alaska Natives (n=265) since 1992 have tested positive in this survey.

2. Service Trends

African Americans: Providers of services to African American PLWH reported that their client caseloads are predominantly male, with increasing numbers of women entering the service system in the past two years. Similar to epidemic figures, African American survey respondents were significantly more likely than Whites to be female (32% versus 7%) and report heterosexual transmission risk (27% versus 3%). African American survey respondents were equally as likely to live in Seattle as White respondents (81% versus 82%).

In previous years, African American survey respondents were significantly more likely than Whites to report homelessness. In 2003, this gap has narrowed, with 20% of African American respondents reporting homelessness in the past year versus 13% of Whites. Providers of services to African American PLWH noted a somewhat higher rate of homelessness in their caseloads, reporting that 25% to 33% of their African American clients have experienced homelessness.

African American survey respondents reported rates of mental illness that were significantly lower than Whites (44% versus 60%). However, providers reported that a large and growing numbers of their clients suffer from depression. Many clients have long-term histories of mental health problems, although many are resistant to psychotherapy or are in denial about the need to seek professional help.

According to providers, substance use issues continue to be widespread among African American PLWH, with between 50%-75% of clients reported as having substance abuse histories. Crack cocaine is reported as the main drug of choice, followed by heroin. The majority of clients are not engaged in treatment programs. Alcohol abuse is also high in this population, with providers estimating that as many as 75%-90% of their clients abuse alcohol. African American survey respondents were no more likely than Whites to report injection drug use (9% versus 8%), but were almost three times as likely to report using non-injectable cocaine (25% versus 9%).

African Americans were slightly less likely to report themselves as AIDS disabled than White PLWH (54% versus 66%). However, African Americans were significantly more likely than Whites to report not knowing their current T-cell counts (24% versus 5%) or their viral loads (24% versus 6%). Providers noted that many of their African American clients are entering care later in their diagnoses and experiencing declining health.

Providers noted that access to HIV-related medications is not a problem for their African American clients. In prior years, providers reported that adherence with medication regimens was a concern. In 2003, providers noted that client compliance has improved significantly. Some clients, however, continue to demonstrate adherence challenges due to medication side effects and substance use.

Despite these positive changes, African American PLWH survey respondents continue to be significantly less likely than Whites to be taking antiviral medications (56% versus 77%). In previous years, African American PLWH were also less likely than Whites to be taking protease inhibitors, medications to treat or prevent opportunistic infections, and medications for HIV-

related side effects. These disparities have lessened considerably in the past two years, with the rate of African Americans taking each of these medications being fairly similar to Whites. African American survey respondents reported higher utilization rates of most services than did White consumers. African Americans were significantly more likely than Whites to use a wide variety of services, including help finding housing (46% versus 28%), peer or client advocacy (50% versus 28%), emergency financial assistance (55% versus 30%), treatment adherence support (54% versus 35%), one-on-one peer support (47% versus 27%), fresh or canned food programs (62% versus 46%), alcohol and/or non-injection drug use treatment (29% versus 13%), telephone referrals to medical and dental care (64% versus 39%), and adult day health programs (28% versus 14%).

Of note is the growing number of HIV+ African refugees who have immigrated to King County. On the 2003 provider survey, respondents reported that three percent of their aggregate consumer caseloads were foreign-born Africans. The largest groups are from Ethiopia and Eritrea, but many other African countries are represented. Twenty-five of the 182 provider survey respondents (14%) reported seeing one or more clients whose primary language was an African dialect (e.g., Eritrean, Somali, Swahili, etc.). Approximately one-third of these clients are women. Most of the African PLWH live in Seattle's Rainier Valley or in South King County.

Providers of services to African refugee PLWH report that their clients are generally in good health. Once introduced to the HIV care system, the clients have had good access to medical care and prescription medications. Co-morbidities such as mental illness and substance use are rare in this population.

"I always think I am alone. I think people are afraid. I've decided never to enter into any more relationships, because I don't want to pass on HIV. My case manager says it can be safe, but I'm afraid." (African immigrant PLWH)

Latino/Latinas: On the 2003 provider survey, respondents reported a higher percentage of Latino/a clients than in any previous survey year. The overall percent of Latino/a clients rose from 8% in 2001 to 11% in 2003, with the number of clients reported as being primarily Spanish speaking increasing from 5% in 2001 to 7% in 2003.

Providers of services to Latino/a PLWH reported that their client caseloads are increasingly female (between 10%-33% of total reported caseloads). While the difference is not as marked as with African American survey respondents, Latino/a survey respondents were significantly more likely than Whites to be female (18% versus 7%) and to have been exposed to HIV through heterosexual contact (39% versus 3%).

Hispanic consumer survey respondents were significantly more likely than Whites to report living in South King County (24% versus 9%). Providers reported that most of their male Latino clients reside in Seattle, although a higher proportion reside in non-Seattle King County than White males. Hispanic female PLWH are dispersed throughout South King County. Latino/a consumer survey respondents were over twice as likely as White PLWH to report homelessness in the past year (30% versus 13%).

Severe mental illness does not appear to be as predominant in this population as in other populations. Providers do report that clinical depression is fairly common (and increasing), although few clients access treatment for it. Forty-one percent of Latino/a PLWH reported being diagnosed with some form of mental illness, including clinical depression. This rate is still significantly lower than for Whites (60%).

Substance use seems to be less widespread in the Latino/a PLWH population than among Whites or African Americans. Rates of injection and non-injectable drug use are less than half those reported in these other populations. Providers noted that alcohol abuse is the “drug of choice” for many of their Latino/a clients.

No trends emerged regarding the point at which clients entered care, with providers seeing clients along the entire spectrum of HIV disease. HIV-related health status was also reported as variable, although Latino/a survey respondents were significantly less likely than Whites to report being AIDS disabled (49% versus 66%). Consistent with prior years, Latino/a clients were four times more likely than Whites to be unaware of their T-cell counts (20% versus 5%) and more than three times more likely to be unaware of their viral loads (20% versus 6%).

Providers noted few problems for their clients in accessing HIV-related medications. However, knowledge of treatment options is relatively low, particularly for female clients. As first reported in 2001, adherence problems with HAART regimens continue to be high. The percent of Latino/a PLWH who reported taking at least one type of HIV-related medication was slightly lower than for Whites, but not statistically significant.

Unlike previous years, Latino/a survey respondents reported higher utilization rates than White PLWH in most service categories. Latino/a consumers were significantly more likely than Whites to use help finding housing (46% versus 28%), help paying rent (57% versus 39%), grocery vouchers (40% versus 26%), telephone referrals to medical and dental care (64% versus 39%), and adult day health programs (44% versus 14%). Not surprisingly, Latino/a consumers were significantly more likely than other PLWH sub-populations to use interpreter services (52% of Latinos/as versus 7% of all other consumers). Consistent with provider reports, Latino/a PLWH demonstrated significantly lower utilization of mental health services (37% versus 58% of Whites), due largely to cultural norms against seeking this type of assistance.

Asian/Pacific Islanders: Providers report seeing very small numbers of A/PI clients. HIV transmission is predominantly related to MSM activity among male A/PI clients and heterosexual risk for female A/PI. No significant differences emerged regarding sex and mode of transmission among A/PI survey respondents (n=21) and Whites. Clients represent a wide spectrum of Asian nationalities and languages, primarily Vietnamese, Cambodian, Chinese and Thai. Although most clients speak at least limited English, language barriers continue to be an issue for recent immigrants.

Providers reported that many of their clients reside in South Seattle and South King County. A/PI consumer survey respondents were slightly more likely than Whites to reside in non-Seattle King County. Rates of homelessness in this population are also reported as being similar to

White PLWH.

Providers noted a high rate of depression among their A/PI clients, with lower rates of other mental illnesses compared to other populations. Clients were described as generally resistant to seeking professional mental health counseling, primarily due to cultural norms. A significantly lower percentage of A/PI survey respondents reported having been diagnosed with mental illness than did Whites (38% versus 60%).

Substance use appears to be far less common among A/PI PLWH than in other populations. Several providers reported no active substance use (including alcohol abuse) among their A/PI client caseloads. No A/PI survey respondents reported using injection drugs, and the rate of cocaine use was less than half that for White PLWH. Reported alcohol abuse was lower than for all other populations.

“I am living with HIV. Like diabetes or renal failure, it is my constant and unwelcome companion, but I feel we walk together. Sometimes whistling, sometimes silent, we are not afraid.” (Asian MSM PLWH)

Providers report that their A/PI clients who are more integrated into the larger community and who do not have language and cultural barriers are seeking services from a wide variety of HIV/AIDS service providers. Those clients who are first generation A/PI are more likely to restrict their services to agencies targeting Asian communities. Service utilization among these clients is reported to have risen somewhat in the past two years, but cultural issues and lack of trust in mainstream providers remain as barriers.

A/PI survey respondents reported similar utilization rates as White PLWH in most service categories. Utilization rates for A/PI were significantly higher than Whites for case management (90% versus 73%), peer or client advocacy (79% versus 28%), and one-on-one emotional support (47% versus 27%). A/PI clients were also more likely than White PLWH to use interpreter services (29% versus 4%). Consistent with provider reports, A/PI PLWH were significantly less likely than Whites to use mental health services (30% versus 58%).

Native American/Alaska Natives: Providers of service to Native Americans and Alaska Natives report that their caseloads are predominantly male. Transmission risk among men is predominantly through homosexual activity, although these men may not self-identify as gay or bisexual. Among women, heterosexual transmission is most common. Among the small number of Native American/Alaska Native survey respondents (n=10), injection drug use was a relatively more common mode of transmission than sexual transmission.

The majority of Native American PLWH live in Seattle. Providers report that at least half of their Native American clients have experienced homelessness in the past year. Survey respondents and focus group participants (n=5) also reported high rates of prior homelessness.

Providers report high rates of mental illness and substance use in the Native American PLWH population. Clinical depression is common, as are paranoid episodes secondary to substance use. Alcohol abuse is reported to be widespread among the Native American PLWH population.

Providers noted that approximately 75% of their Native American clients are current or former substance users, with crystal meth, crack cocaine and heroin being the “drugs of choice.” Providers reported that most of their Native American clients enter care late in their AIDS diagnosis. These clients are referred into HIV care through inpatient hospitalizations, the TB clinic, and from substance use treatment programs. Due to the small number of Native American survey respondents (n=10), it is not possible to derive comparisons of HIV-related health status and medication usage to other populations.

Native American survey respondents did report utilization rates that were fairly similar to White PLWH, although statistical comparisons are not possible. Providers noted that it often takes a longer period of time to engage Native American clients in services, sometimes requiring years of concerted effort. This is due to several factors, including cultural issues related to privacy and confidentiality, homelessness and chemical dependency. Once trust has been developed between provider and consumer, Native American clients tend to access a wide variety of services. Housing assistance is reported to be the most frequently requested service for this population.

3. Service Priorities

African Americans: Primary medical care tied with emergency financial assistance as the number one service priority for African American survey respondents (Table 26). These services were followed by case management, oral health care, the AIDS Drug Assistance Program, and housing assistance and housing related services.

African American consumers were significantly more likely than White PLWH to prioritize emergency financial assistance (65% versus 38%). African Americans were also significantly more likely to prioritize child care than Whites (15% versus 0%), due to the higher percentage of African American respondents who were women.

Table 26. Service Priorities: African Americans (n=55; 4 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1 (tie)	Ambulatory/outpatient medical care	36	65%
1 (tie)	Emergency financial assistance	36	65%
3	Case management	33	60%
4	Oral health care	32	58%
5 (tie)	AIDS Drug Assistance Program	29	53%
5 (tie)	Housing assistance/related services	29	53%
7	Psychosocial support	23	42%
8	Health insurance	18	33%
9	Client advocacy	17	31%
10 (tie)	Legal services	15	27%
10 (tie)	Food bank/home-delivered meals	15	27%

Latino/Latinas: Latino/a survey respondents ranked housing assistance and housing related services as their number one service priority (Table 27). This was followed by oral health care, case management, emergency financial assistance, and health insurance. It is interesting to note that Latinos/as were the only consumer sub-population not to rank primary medical care among their top five service priorities (ranked 6th).

Table 27. Service Priorities: Latino/Latinas (n=53; 3 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	33	69%
2	Oral health care	28	58%
3	Case management	27	56%
4	Emergency financial assistance	26	54%
5	Health insurance	26	54%
6	Ambulatory/outpatient medical care	25	52%
7	AIDS Drug Assistance Program	23	48%
8	Food bank/home-delivered meals	16	33%
9 (tie)	Client advocacy	13	27%
9 (tie)	Psychosocial support	11	23%

Latino/a consumers were significantly more likely than Whites to prioritize housing assistance and related services (74% versus 45%). Providers noted that housing needs among their clients have increased in recent years, particularly due to the rising number of non-resident Latino/as who have moved into in King County. Latino/as were also significantly more likely than Whites to prioritize treatment adherence support programs (15% versus 6%). As previously noted, information about HIV treatments is generally more available in English and knowledge levels of HIV disease and treatment options are generally lower among Hispanic female PLWH.

Asian/Pacific Islanders: The limited number of Asian/Pacific Islander survey respondents (n=21) identified similar service priorities as other consumer sub-populations. The top service priority identified by A/PI PLWH was the AIDS Drug Assistance Program, followed by ambulatory medical care, oral health care, and emergency financial assistance (Table 28). It is interesting to note that Asian/Pacific Islander PLWH were the only consumer sub-population not to rank case management among their top five service priorities (ranked tied for 9th).

In particular, providers of services to this population stressed the importance of delivering services in a culturally competent manner, which takes into account the client's culture of origin. Because the range of languages spoken in the Asian/Pacific Islander communities is extensive, this requires that providers have access to a broad range of Asian language interpreters.

**Table 28. Service Priorities: Asians/Pacific Islanders
(n=19; 2 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	AIDS Drug Assistance Program	16	84%
2 (tie)	Ambulatory/outpatient medical care	13	68%
2 (tie)	Oral health care	13	68%
4	Emergency financial assistance	11	58%
5 (tie)	Client advocacy	8	42%
5 (tie)	Transportation	8	42%
5 (tie)	Health insurance	8	42%
5 (tie)	Housing assistance/related services	8	42%
9 (tie)	Case management	7	37%
9 (tie)	Psychosocial support	7	37%

Native American/Alaska Natives: In general, the limited number of Native American survey respondents identified similar service priorities as other consumer sub-populations. These included primary medical care, the AIDS Drug Assistance Program, case management, emergency financial assistance and oral health care.

Providers of services to Native Americans and Alaska Natives noted that case management and client advocacy were extremely important for their clients. Most of their clients are dually or triply diagnosed (HIV, mental illness and chemical dependency), and need assistance with housing, financial and insurance issues. As a result, these clients may require more time and resources than other PLWH in order to help them access and maintain services.

4. Service Gaps

“I am very paranoid about sharing my health status with anyone. My T-cell count is low and my viral load is high. I’ve only told those I have to, to try and survive.” (African American female PLWH)

African Americans: African American PLWH ranked emergency financial assistance, housing assistance, psychosocial support, legal services and child care among their top five service gaps (Table 29). Within the emergency financial assistance category, African Americans reported fairly equal gaps in grocery vouchers (22%) and help paying for utilities (21%). In the housing category, African American clients were more likely to identify a gap in help paying rent (27%) than in help finding housing (9%).

As first seen in 2001, African American PLWH were fairly similar to White consumers in their identification of service gaps. The only categories in which African American consumers

identified significantly greater gaps than Whites are child care (17% versus 4%) and transportation (15% versus 5%).

Table 29. Service Gaps: African Americans (n=59)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	16	27%
2	Housing assistance/related services	14	24%
3 (tie)	Psychosocial support	13	22%
3 (tie)	Legal services	13	22%
5	Child care	10	17%
6	Transportation	9	15%
7 (tie)	Client advocacy	8	14%
7(tie)	Food bank/home-delivered meals	8	14%
9	Buddy/companion care	7	12%
10	AIDS Drug Assistance Program	6	10%

Latino/Latinas: Consistent with rankings from the past two rounds of surveys, Latino/a survey respondents ranked emergency financial assistance as the largest service gap in the Continuum of Care. This was followed by legal services, housing assistance, psychosocial support and alternative/non-Western therapies (Table 30). Within the emergency financial assistance category, Latino/as noted a slightly higher gap in grocery vouchers (38%) than in help paying for utilities (33%).

Table 30. Service Gaps: Latino/Latinas (n=56)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	22	39%
2 (tie)	Legal services	17	30%
2 (tie)	Housing assistance/related services	17	30%
4	Psychosocial support	16	29%
5	Alternative, non-Western therapies	15	27%
6	Mental health services	14	25%
7	Client advocacy	13	23%
8	Food bank/home-delivered meals	12	21%
9	Oral health care	10	18%
10 (tie)	Child care	9	16%
10 (tie)	Referral for health care services	9	16%

Latino/Latina consumers identified statistically higher service gaps than other populations in a broader range of service categories. Among the categories in which these consumers identified

greater gaps are legal services (30% versus 17% of all other consumers), mental health services (25% versus 12%), client advocacy (23% versus 13%), food and meal programs (21% versus 11%), child care (16% versus 5%), and health education and risk reduction (11% versus 3%).

Asian/Pacific Islanders: A/PI consumer survey respondents ranked housing services and emergency financial assistance as tied for their top service gap, followed by legal services (Table 31). Due to the relatively low number of A/PI clients who identified service gaps, no category emerged as a significantly higher gap than for other sub-populations.

**Table 31. Service Gaps: Asians/Pacific Islanders
(n=21)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1 (tie)	Housing assistance/related services	6	29%
1 (tie)	Emergency financial assistance	6	29%
3	Legal services	4	19%
4 (tie)	Alternative, non-Western therapies	3	14%
4 (tie)	Transportation	3	14%
4 (tie)	Oral health care	3	14%
4 (tie)	Mental health services	3	14%
8	Food bank/home delivered meals	2	10%

Note: 10 services received one mention each as a service gap

As with Latinos and Native Americans, providers stated that service gaps were largely dependent on the degree of integration into the mainstream culture exhibited by their clients. For clients who are familiar with and comfortable using HIV/AIDS services, few gaps exist. However, for those who are recent immigrants or for whom English is not their first language, effective case management and client advocacy is vital in accessing medical and social services.

Native American/Alaska Natives: The low number of Native American/Alaska Native survey respondents (n=10) makes it impossible to constructively rank service gaps for this sub-population. Nevertheless, Native American PLWH ranked emergency financial assistance, oral health care and psychosocial support as tied for the highest service gap. Each of these services was identified as a gap by four of the ten survey respondents. As previously mentioned, providers of services to this population noted that the main challenge in working with this population is developing trust as a prelude to engagement in care and services.

“I have a very small income. I am seriously struggling to maintain my private health insurance payment, which has gone up to almost \$500 a month. I need help, but I am not yet disabled and I want to keep my health insurance as long as possible.” (Native American male PLWH)

5. Unmet Need for Medical Care

African Americans: Ninety-two percent of African American respondents to the consumer survey reported currently receiving primary care for their HIV infection, similar to rates reported by Whites and other sub-populations. All of the participants in the African American focus group (n=6) were currently engaged in primary care and none had experienced any notable challenges in accessing care in King County.

Several participants in the African American focus group stated that they were aware of HIV-infected peers who were not currently accessing medical care. They suggested that the main barrier for these individuals was denial about their infection. Other barriers included fear of being stigmatized in the community and substance use issues. They felt that heightened visibility of HIV information and education in the African American community was needed to overcome these barriers. Providers were in agreement with these opinions, noting that access to care was relatively easy for their clients once they were ready to engage in services.

The main barrier identified to enrolling and maintaining African immigrant PLWH in medical care was navigating complicated insurance systems. Most of these clients are in relatively stable health and many are receiving health care coverage through their employers. However, members of this population are generally unfamiliar with the American health care system, and are less able to make informed choices about their care and coverage options.

Latinos/as: Ninety-four percent of Latino/a PLWH respondents to the consumer survey reported currently receiving primary care for their HIV infection. All of the participants in the Latino/a focus group (n=6) were currently engaged in primary care and none had experienced significant challenges in accessing care in King County. They were particularly grateful to their case managers who had helped them access services and medical care.

“We need more Spanish speaking medical providers so that you don’t have to have a third person interviewer in your business.” (Latina female PLWH)

Latino/a focus group participants expressed frustration and concern that they had not been tested for HIV earlier in their disease progression. Many of these individuals were surprised to find out that HIV testing had not been part of their routine medical care. As a result, several had experienced hospitalizations and severe symptoms before it was suggested to them that they be tested for HIV. They were surprised that confidentiality issues in the United States appear to supercede what they perceive to be necessary medical care. This highlights the need for providers to address potential HIV risk in the Latino/a population, and incorporate informed HIV prevention, testing and counseling into their service delivery.

Providers reported barriers in helping their Latino/a clients access medical coupons and insurance coverage. Their clients are unfamiliar with the DSHS and DOH systems, and find the paperwork and bureaucracy confusing.

Asians/Pacific Islanders: Similar percentages of Asian/Pacific Islanders reported medical care utilization as other sub-populations (94%). As previously noted, it was not possible to convene an A/PI focus group due to lack of participant registration. However, providers reported that

most of their A/PI clients are engaged in medical care and that few access barriers exist for their enculturated clients. Language and cultural issues continue to serve as barriers for non- or limited-English speakers. It is just as important for these clients to trust their interpreters as it is that they trust their medical and social service providers. This may necessitate a “one client/one interpreter” system, because there are many Asian communities in King County, and confidentiality within each of these can be a significant concern.

Providers also noted that preventive medical care is not a common cultural concept. As a result, clients may only access care when they are very sick. This highlights the need for increased education and outreach in A/PI communities regarding the benefits of early intervention and treatment for HIV infection.

Native Americans/Alaska Natives: Nine of the ten Native American/Alaska Native survey respondents reported current utilization of primary medical care. All of the Native American focus group participants (n=5) were engaged in medical care and had seen a doctor within the past six months. Several participants noted that they had specifically moved to Seattle to access medical care, because they felt that the quality of HIV care available to them in the city was superior to what was available on their reservations or in other rural areas.

In prior years, Native American focus group participants revealed that they were aware of other members of their community who were HIV-infected but not engaged in care. The 2003 focus group did not express similar sentiments. Providers stressed that access to care was not an issue for their Native American clients, but that developing trust with these clients was an extended process that necessitated persistent and ongoing efforts.

Estimates of PLWH who are “not in care”: In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened a work group across Titles I and II. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). (A comprehensive discussion of how the Seattle EMA planned its “not in care” estimate process and derived its figures is contained in Part IV, Section H, “Unmet Need for Medical Care.”)

Estimates of unmet need included sub-population analysis based on sex, race/ethnicity and HIV/AIDS status. As a result, it is possible to quantify the number of King County PLWH who are persons of color who are believed to be not in care (defined locally as not having had a T-cell or viral load test in the past twelve months). Based on adjusted laboratory report data, the following estimates have been developed:

- 23.2% of all King County African American PLWH who are aware of their serostatus are currently “not in care.” This represents approximately 200 African Americans. (95% confidence range: 173 low estimate and 229 high estimate).
- 28.2% of all King County Latino/a PLWH who are aware of their serostatus are currently “not in care.” This represents approximately 131 Latino/as. (95% confidence range: 109 low estimate and 155 high estimate).
- 15.7% of all King County Native American/Alaska Native PLWH who are aware of their

serostatus are currently “not in care.” This represents approximately 15 Native Americans/Alaska Natives. (95% confidence range: 8 low estimate and 24 high estimate).

- 32.8% of all King County Asian/Pacific Islander PLWH who are aware of their serostatus are currently “not in care.” This represents approximately 42 A/PI PLWH. (95% confidence range: 30 low estimate and 56 high estimate).

Based on the UCSF framework, an estimated 23.5% of White PLWH are believed to be “not in care.” Although the estimated “not in care” percentages are lower for Native American PLWH and slightly higher for other racial/ethnic sub-groups, these differences are not statistically significant.

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project include information about persons who received a “late diagnosis” with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons across racial/ethnic categories who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that:

- 32.2% of African American PLWH (91 out of 283) who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 35.2%.
- 39.2% of Latino/a PLWH (58 out of 148) who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 47.1%.
- 28.6% of Asian/Pacific Islander PLWH (10 out of 35) who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 28.6%.
- 33.3% of Native American/Alaska Native PLWH (11 out of 33) who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 42.9%.

Comparable figures for White PLWH indicate that 19.4% (94 out of 485) received late diagnoses of HIV during the 1996-2001 time period. In 2001, the percentage of late diagnoses among White PLWH was 28.3%. Within the various racial/ethnic categories, Latinos are more likely to receive late diagnoses, both cumulatively and among recently tested persons.

These figures suggest that persons of color across all racial/ethnic categories are more likely than White PLWH to receive late diagnoses of HIV. Increased counseling and testing efforts directed towards communities of color are necessary, as are heightened culturally-specific education efforts to inform individuals at risk about the benefits of early intervention, treatment and medical care.

D. Women

“There needs to be more available for the straight population, like more support groups and social activities. Remember this disease is not just a gay man’s disease and the heterosexual communities need help, too.” (African-American female PLWH)

1. Epidemiologic Profile

In King County, women represent 9% of the total cumulative HIV/AIDS cases. However, the proportion of AIDS cases among women and the number of women living with HIV infection have increased in recent years, and this trend is expected to continue. Women with HIV/AIDS tend to be younger than men, most acquire HIV through heterosexual contact, and women of color are disproportionately affected.

Population sizes: According to the 2000 census, 743,804 women age 13 and over live in King County. The estimated number of HIV positive adult or adolescent women in King County is approximately 750. This estimate includes HIV-infected women who have not yet been diagnosed and a smaller number of women who have tested HIV positive but have not been reported. The estimated number of women in King County who are at risk for HIV because they are drug injectors or sex partners of drug injectors is 9,000-15,000.

Status and trends in AIDS cases: As of 12/31/2002, there were 451 women age 13 or over reported to Public Health and presumed living with HIV or AIDS in King County. This is 9% of the total of 5,115 King County residents living with HIV or AIDS. Women represent 5% of the cumulative AIDS cases and 11% of the HIV non-AIDS cases diagnosed and reported in King County.

The number of HIV/AIDS cases diagnosed in King County women continues to increase. Cases in women have risen from about 30 women diagnosed with HIV annually from 1988-1990 to 50 per year in 2000-2002. The percent of King County HIV/AIDS cases occurring in women has increased over time, with female cases rising from 2% of total cases in 1983-1987 to 12% of cases diagnosed in 2000-2002.

The majority (64%) of women living with HIV/AIDS in King County acquired HIV through heterosexual contact. Thirty-two percent acquired HIV through the use of injection drugs, and 4% by blood transfusion. These percentages are calculated after adjusting for the 24% of all cases among females that are reported without known risk.

Among King County women living with HIV/AIDS, the prevalence rate for African American women is thirteen times higher than for White women. The prevalence rate is nine times higher among Native American/Alaska Native women and three times higher among Hispanic than in Whites. The rate is about one-third as high among Asian/Pacific Islander women.

HIV seroprevalence: Based on estimates of 750 HIV-infected women in King County, it is estimated that 0.1% of all women age 13 and over are infected. The rate is higher among African American, Hispanic and Native American women than in White women.

Sub-group highlights: Pregnant women and children: Only 32 pediatric infections (age 0 to 12 years at the time of HIV diagnosis) have ever been reported in King County. These represent 0.4% of cumulative diagnosed cases. The most recent case of documented perinatal transmission was in 1997. None of the estimated ten to fifteen infants born to HIV-infected mothers annually since 1997 have become infected.

2. Service Trends

Providers noted that the majority of women with HIV on their caseloads are in their 30's and 40's. Increasing numbers of younger women are also seeking services, especially women in their 20's. Many of these younger female clients have dependent children.

As in prior years, providers report that the majority of their female clients acquired HIV through heterosexual transmission. In many cases, the client's male partner was identified as having a history of injection drug use. Although the number of women reported as being IDU themselves has increased, the change has not been significant over the past two years.

Most King County female PLWH are Seattle residents, although a higher percentage of female clients reside in South King County than is seen among male PLWH. Female consumer survey respondents were almost three times more likely to be South King County residents as male respondents (27% versus 10%). Providers also noted that they are seeing an increase in homeless female PLWH. Female survey respondents reported more than twice the rate of homelessness in the past year as did male respondents (31% versus 14%).

Service providers report that a high percentage of their female clients are multiply diagnosed (HIV, mental illness and/or chemical dependency). Sixty percent of female consumer survey respondents report that they had been diagnosed with a mental illness, including clinical depression. Providers noted that many of their female PLWH clients are not engaged with the mental health system, unless the severity of their mental illness is impacting their day-to-day ability to function.

Substance use continues to have a significant impact on the lives of female PLWH. Providers noted that over half of their female clients have histories of substance abuse. This is particularly true of White and African American female PLWH, but much less common among Latinas and Asians/Pacific Islanders. Crack cocaine is the main "drug of choice" for female PLWH substance users, although providers report seeing increasing crystal methamphetamine use in this population.

Consistent with epidemiologic trends, service providers who work with HIV+ women note that a high proportion of their client caseloads are women of color. Providers report that they are seeing increasing numbers of women from all racial categories, particularly African-Americans, Latinas and Native American women. Female consumer survey respondents were almost three times more likely than males to be African American (29% versus 10%) and twice as likely to be of mixed racial backgrounds (12% versus 6%). During the past two years, providers noted that increasing numbers of women from the growing refugee populations in King County are beginning to utilize services. This represents both an overall increase in this PLWH population, as well as the results of ongoing attempts to engage these women in services.

Similar to previous assessment reports, female survey respondents were statistically less likely than males to be AIDS disabled (43% versus 65%). Women were also significantly less likely to report T-cell counts over 500 (12% versus 21%). Female survey respondents were significantly more likely than males to be unaware of their T-cell counts (20% versus 9) and viral loads (25% versus 11%). Providers noted that their younger female clients tend to present earlier in their HIV diagnoses, while older clients continue to enter care later in their diagnosis. The majority of female clients are reported to be in stable health.

Providers noted that their female clients have had relatively few access problems with HIV medications. This sentiment was echoed among female focus group participants (n=5). However, both providers and consumers reported complex adherence issues. These include lack of trust in HIV medications, unstable housing and living situations, and mental health and chemical dependency barriers. In particular, several women of color in focus groups stated that they feel like “guinea pigs” due to having physicians frequently change their medication combinations. Additionally, female immigrants may face cultural challenges when interacting with the medical system.

Despite these adherence problems, the percentage of female survey respondents who reported taking various forms of HIV medications has increased. In 2001, only 59% of female survey respondents reported being on antiviral medications, as opposed to 66% in 2003. The percent of female PLWH who reported taking protease inhibitors rose from 31% in 2001 to 45% in 2003. The gap between the percent of female and males that reported taking antivirals and/or protease inhibitors has also narrowed significantly during the past two years.

Providers reported that their female clients continue to utilize a wider range of social and support services with each succeeding year. However, female respondents on the 2003 consumer survey were slightly less likely to use several key medical care-related services than male PLWH. Women were slightly less likely than men to use primary care (90% versus 94%), the Washington State AIDS Prescription Drug Program (66% versus 71%), and health insurance continuation programs (53% versus 70%). Each of these figures, however, represents higher utilization rates for women from those reported on the 2001 survey, suggesting that increased outreach and enrollment efforts have been successful.

Women were more likely than men to use case management (84% versus 76%). Due to the geographically diverse nature of this population and increasing co-morbidities (mental illness, substance use, homelessness, etc.), ongoing involvement with case management is vital in helping many female PLWH access and maintain care services. Case managers appear to be successful in helping female clients access and maintain services, as female survey respondents demonstrated higher utilization than males of mental health therapy (69% versus 52%), substance use treatment/counseling (injection drug treatment: 14% versus 9%; non-injection treatment: 30% versus 16%) and help finding low income housing (42% versus 32%). Women were also significantly more likely than men to use a wide range of support services, such as one-on-one peer support (64% versus 28%), client advocacy (69% versus 31%), support groups (73% versus 40%) and transportation (51% versus 30%). Emergency financial assistance was also a highly utilized service for women, as 46% reported using grocery vouchers and 52% used help paying for utilities.

3. Service Priorities

Female survey respondents ranked ambulatory medical care and oral health care tied for the number one service priority (Table 32). Other highly ranked priority services include housing assistance, emergency financial assistance, and case management.

Several significant differences in service prioritization were observed based on sex. Women were significantly more likely than men to prioritize psychosocial support (43% versus 30%) and child care (25% versus 1%). Conversely, women were significantly less likely than men to prioritize the AIDS Drug Assistance Program (38% versus 62%) and health insurance (27% versus 44%).

Table 32. Service Priorities: Women (n=60; 5 missing responses)

RANK	SERVICE	# OF VOTES	% OF RESP.
1 (tie)	Ambulatory/outpatient medical care	36	60%
1 (tie)	Oral health care	36	60%
3	Housing assistance/related services	34	57%
4	Emergency financial assistance	33	55%
5	Case management	31	52%
6	Psychosocial support	26	43%
7 (tie)	AIDS Drug Assistance Program	23	38%
7 (tie)	Mental health services	23	38%
9	Client advocacy	22	37%
10 (tie)	Health insurance	16	27%
10 (tie)	Transportation	16	27%

4. Service Gaps

Women ranked child care as the number one service gap, followed by housing assistance, emergency financial assistance, oral health care, legal services and mental health services (Table 33). The overall percentage of women who reported child care as a gap has increased significantly in the past two years, rising from 5% of respondents identifying this service as a gap in 2001 to 31% in 2003.

Statistically significant differences in service gaps based on gender were reported in only two service categories. Thirty-one percent of female respondents noted difficulty in accessing child care, as compared to 3% of males. Women were also more likely than men to identify gaps in transportation (15% versus 6%).

On the FY01 survey, women of color exhibited greater access gaps than White female PLWH in almost all service categories. Data from the 2003 survey suggest this disparity seems to have lessened considerably. The sole service categories in which women of color exhibited significantly greater gaps than White women were child care services (36% versus 11%), housing services (36% versus 17%), legal services (24% versus 6%) and transportation (24%

versus 0%). Latinas, in particular, were more likely to identify service gaps, based largely on language barriers and concerns about confidentiality.

Table 33. Service Gaps: Women (n=65)

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Child care	20	31%
2	Housing assistance/related services	19	29%
3	Emergency financial assistance	18	28%
4 (tie)	Oral health care	12	18%
4 (tie)	Legal services	12	18%
4 (tie)	Mental health services	12	18%
7 (tie)	Food bank/home-delivered meals	10	15%
7 (tie)	Transportation	10	15%
7 (tie)	Alternative, non-Western therapies	10	15%
7 (tie)	Buddy/companion care	10	15%

Data from the 2003 survey were also used to quantify the unmet needs of women. This was accomplished by applying the percent of women identifying service gaps across the population estimate of 451 women reported to Public Health and presumed living with HIV or AIDS in King County. Analysis indicates that approximately 140 women in King County have an unmet need for child care, 130 have an unmet need for housing assistance (particularly for help paying rent), and 125 have an unmet need for emergency financial assistance (including grocery vouchers and help paying for emergency utility bills).

5. Unmet Need for Medical Care

“We need to get the word out that there’s nothing to be ashamed of when you’ve got HIV. Get more people tested and work through the stigma. Make it about health, not death.”
(White female PWLH)

As previously noted, female survey respondents were slightly less likely than males to use primary care (90% versus 94%), the Washington State AIDS Prescription Drug Program (66% versus 71%), and health insurance programs (53% versus 70%). Each of these figures, however, represents increased utilization rates for women from those reported on the 2001 survey.

Providers reported that access to medical care is generally not a problem for their female clients, once they decide to engage in care. Barriers to initial engagement include:

- women living chaotic lives, with multiple challenges (mental illness, homelessness, domestic violence);
- fear of disclosure and loss of confidentiality, particularly for immigrant and refugee women, and

- difficulties in keeping medical appointments, due to lack of child care (particularly care for school age children and/or on an emergency basis), transportation, or being too ill to leave the house with their children

In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened an Unmet Need work group across Titles I and II. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). (A comprehensive discussion of how the Seattle EMA planned its “not in care” estimate process and derived its figures is contained in Part IV, Section H, “Unmet Need for Medical Care.”)

Estimates of unmet need included sub-population analysis based on sex, race/ethnicity and HIV/AIDS status. As a result, it is possible to quantify the number of female PLWH in King County who are believed to be not in care (defined locally as not having had a T-cell or viral load test in the past 12 months). Based on adjusted laboratory report data, it is estimated that 16.3% of all King County female PLWH who are aware of their serostatus are currently “not in care.” This represents approximately 89 women (95% confidence range: 71 low estimate and 109 high estimate.) The percent of female PLWH who meet the “not in care” definition is lower than for male PLWH (16.3% versus 24.7%).

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project include information about persons who received a “late diagnosis” with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that 37 out of 184 (20.1%) female PLWH who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 26.7%. This suggests that increased counseling and testing efforts directed towards at-risk women are necessary.

Female focus group participants (n=5) were all currently enrolled in primary medical care, and had all seen their providers within the past six months. None reported major barriers to accessing medical care within the past five years, either for themselves or for their peers. However, several female participants noted that changes in Medicaid had effected their ability to access some HIV medications. These women noted that their case managers were able to help them negotiate the system and ultimately restore their access to the drugs.

Several focus group participants reported knowing peers who were HIV+ (or at high risk for HIV) who were not engaged in medical care. The main reason they believed these women have not entered care was denial of their HIV risk or serostatus. They recommended increased education and outreach to women, with emphasis on informing women of the benefits and availability of medical care and prescription drugs.

E. Homeless Persons

“Being in a shelter was a nightmare. You’ve got to carry all your personal belongings with you. Everyone’s got an attitude, everyone’s always mad! I’d rather sleep in a tent outdoors or in a van.” (Homeless male PLWH)

1. Epidemiologic Profile

Although there have been no local population-based surveys of HIV infection in the homeless population in King County, studies from other areas of the country indicate that homeless men and women are at higher risk for HIV. Homeless people reported with AIDS in King County were more likely to be persons of color and to have been exposed through injection drug use compared to those who were not homeless.

Population sizes: The McKinney Act (Public Health Law 100-628, November 7, 1988) defines homelessness as:

“A homeless person is an individual who lacks a fixed, regular, and adequate residence or an individual who has a primary night-time residence that is either (a) a supervised or publicly operated shelter designed to provide temporary or transitional living accommodation or (b) a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.”

Approximately 5,500 persons are homeless in King County on any day, of which 500-2,000 are youth/young adults. An estimated 25,000 persons have experienced homelessness in the past year in King County.

Among reported HIV/AIDS cases, homelessness is defined as having no resident zip code at time of HIV or AIDS diagnosis. This definition undercounts the number of homeless AIDS cases if, for example, the zip code of a shelter, friend’s home or provider’s office is reported as the zip code of residence. Eighty-nine (2%) of the 5,115 King County residents living with HIV or AIDS as of 12/31/2002 were reported as homeless. It is estimated that as many as 600 PLWH in King County may experience homelessness during any given year.

Status and trends in AIDS cases: Among homeless persons with HIV/AIDS, 49% were persons of color and 65% were injection drug users (including MSM/IDU), compared to 27% and 15%, respectively, among persons who were not homeless at time of diagnosis (Table 34).

Homelessness is a particular concern among injection drug users in King County. In a Public Health survey of 1,824 drug injectors at the King County Correctional Facility interviewed between 8/98 and 7/02, 60% reported having no permanent residence prior to their arrest.

HIV seroprevalence: In 1998, AIDS Housing of Washington analyzed the results of more than 5,650 surveys of PLWH conducted in twelve regions across the country between 1994-1998. Seven percent of all respondents reported that they were living on the streets, in a shelter, or in a residential hotel/motel at the time they completed the survey, and 41% of respondents had been homeless at some point in time.

Table 34. Demographic characteristics by homeless status of King County residents living with HIV/AIDS as of December 2002

	Homeless at time of diagnosis		Not Homeless at time of diagnosis	
	Number	%	Number	%
SEX				
Male	76	(85)	4,572	(91)
Female	13	(15)	454	(9)
RACE/ETHNICITY				
White	45	(51)	3,687	(73)
African American	30	(34)	740	(15)
Latino/Latina	7	(8)	405	(8)
Asian/Pacific Islander	0	(0)	108	(2)
Am. Indian/AK Native	7	(8)	77	(2)
Unknown Race	0	(0)	9	(<1)
EXPOSURE				
Male/male sex	22	(25)	3,562	(71)
Injection drug use (IDU)	33	(37)	311	(6)
IDU & male/male sex	25	(28)	440	(9)
Heterosexual contact	3	(3)	328	(7)
Undetermined/Other	6	(7)	385	(8)
TOTAL CASES	89	(100)	5,026	(100)

2. Service Trends

(NOTE: Due to difficulty in obtaining survey responses from consumers who were currently without a residence, the needs assessment survey asked consumers if they were currently homeless (without a permanent residence) or had been homeless during the past twelve month period. In this manner, it was anticipated that the survey would capture data from individuals for whom homelessness was either a recent or current problem. Of the 483 survey respondents, 82 (17%) reported homelessness within the past year. This represents a 41% increase over 2001 in the number of survey respondents reporting homelessness.)

Consistent with the previous two rounds of needs assessments, providers of services to homeless adults with HIV reported that their client caseloads are largely male, although increasing numbers of homeless female PLWH have entered the service system in the past two years. On the 2003 consumer survey, homeless respondents were twice as likely as non-homeless respondents to be female (24% versus 12%).

Providers noted that it was very difficult to determine the mode of HIV transmission for many of their homeless clients, due to multiple sexual and substance use risk factors. MSM sexual activity continues to be fairly common among the men, although many do not identify as gay or bisexual. Trading sex for money, drugs or shelter contributes to high-risk behaviors among both men and women in this population.

The population of homeless PLWH is more racially diverse than the general population of PLWH in the EMA. Only 45% of homeless PLWH respondents to the consumer survey reported themselves as White, with 21% being Latino/a, 15% African-American, and 5% each Native American, Asian/Pacific Islander and mixed race. In contrast, 64% of non-homeless respondents were White. Providers also reported that a higher percentage of their homeless clients are persons of color than are seen in non-homeless PLWH.

Rates of mental illness and/or chemical dependency in the population are extremely high. Homeless PLWH who responded to the 2003 consumer survey were significantly more likely than other PLWH to report being diagnosed with mental illness (70% versus 52%). Providers of services to homeless PLWH report that almost all of their clients have mental health issues, with the large majority being undiagnosed and untreated. Unlike other populations, in which clinical depression is the primary presenting mental illness, homeless PLWH present with a full range of psychiatric diseases. These include high (and increasing) levels of bipolar, anxiety and personality disorders.

According to King County epidemiology statistics, 65% of homeless PLWH have a history of injection drug use. Multi-drug use is also increasing among homeless PLWH, with some providers estimating that as many as 80% of their homeless clients are current or former substance users. Homeless respondents to the consumer survey were significantly more likely than other consumers to report histories of injection drug use (22% versus 5%) and alcohol abuse (31% versus 18%). Use of non-injection drugs was also high among homeless survey respondents, with the main “drugs of choice” being cocaine (reported by 34% of homeless PLWH) and methamphetamine (26%).

Providers noted that their homeless PLWH clients are generally less likely to be engaged in substance use treatment than in past years. Access to treatment remains difficult due to long waiting lists, complicated assessment processes, fewer detox beds and the closure of several King County substance use treatment programs (both out-patient and residential). For most clients, adherence to substance use treatment goes hand-in-hand with housing stability. If the client is released from in-patient treatment back to the streets, the odds of relapse increase dramatically.

Histories of incarceration are also common among this population. Homeless survey respondents were almost six times as likely as non-homeless PLWH to have been incarcerated in the past year (23% versus 4%). Providers report that the majority of their homeless clients have spent some time in jail or prison, with many clients having extensive criminal histories.

Data from the FY 2003 consumer survey reveal several differences between HIV-related health care status based on homelessness. Homeless PLWH were more than twice as likely as other PLWH to not have had a recent T-cell count or not know the results of their count (21% versus 9%) and to not have had a recent viral load test or know the results of the test (23% versus 11%). Homeless respondents were also significantly less likely to be receiving all forms of HIV medications: antiretrovirals (51% versus 76%), protease inhibitors (35% versus 49%) and medications for HIV-related side effects (28% versus 40%).

Providers of services to homeless PLWH and homeless focus group participants (n=11) noted that once homeless PLWH become connected to the care service system, either through the efforts of outreach case managers or placement in transitional or permanent housing, utilization rates are comparable to non-homeless PLWH. In fact, homeless PLWH were more likely than other PLWH to use case management services (86% versus 75%). This may explain the fact that homeless survey respondents reported utilization rates that were fairly similar to those of non-homeless PLWH. In several categories, homeless respondents reported higher rates of utilization, such as peer or client advocacy (54% versus 32%), support groups (57% versus 43%), and one-on-one peer support (47% versus 30%).

Homeless PLWH were also more likely than other consumers to utilize all forms of food-related assistance (fresh or canned food programs: 65% versus 46%, prepared meals: 53% versus 37%, and grocery vouchers: 55% versus 27%). The percent of homeless consumers who reported accessing injection drug use counseling or treatment (23%) and counseling or treatment for alcohol and other drugs (36%) also represents higher utilization rates than seen on previous surveys.

3. Service Priorities

Consumer survey respondents who reported themselves as currently homeless (or homeless within the past year) listed housing assistance and housing related services as their highest priority (Table 35). Other services that were ranked among the top five highest priorities were primary medical care, emergency financial assistance, oral health care and case management.

**Table 35. Service Priorities: Homeless Persons (Current or in past year)
(n=81; 1 missing response)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	55	68%
2	Ambulatory/outpatient medical care	52	64%
3	Emergency financial assistance	48	59%
4	Oral health care	45	56%
5	Case management	44	54%
6	AIDS Drug Assistance Program	38	47%
7	Food bank/home-delivered meals	29	36%
8	Mental health services	25	31%
9	Psychosocial support	23	28%
10	Health insurance	21	26%

Homeless consumers were significantly more likely to prioritize housing assistance than other PLWH (68% versus 46%). The need for affordable, safe housing programs is obviously a high priority for most homeless individuals, particularly for homeless men and women living with HIV. Participants in the homeless PLWH focus group expressed concern that living in shelter situations as a person with HIV is extremely difficult. They expressed fears about being “outed” as HIV+ in shelters, by being seen taking HIV medications or overheard speaking on the phone

to medical and social service providers. Personal safety in shelter situations was also a concern, especially for homeless female PLWH. Several consumers also spoke of overt discrimination they experienced at the hands of shelter staff who did not want HIV+ individuals in their facilities. However, for persons who have not lived in stable housing situations for a long period of time, the transition into permanent housing can also be difficult without readily accessible support services. Providers emphasized the need to develop housing services that provide on-site access to substance use treatment, mental health counseling, and medication management.

4. Service Gaps

“Thus far, King County and Seattle in general seem to have really good services both for homeless and HIV positive people. Easier access for dental care would be beneficial and help with food is always needed, as well.” (Homeless male PLWH)

Current or formerly homeless consumers ranked emergency financial assistance as the service they most frequently needed but could not get (Table 36). Financial assistance was followed by housing services, legal services, oral health care, food programs, and alternative therapies.

Data from each of the past three rounds of consumer surveys suggested that service gap disparities between homeless PLWH and non-homeless PLWH had begun to decrease. However, the 2003 consumer survey revealed that access gaps for homeless PLWH in several categories have begun to reappear. The major service categories in which significantly greater gaps appeared were emergency financial assistance (particularly for grocery vouchers), with 45% of homeless PLWH reporting service gaps, versus 34% of other consumers, housing services (35% versus 24%), food/meal programs (20% versus 13%), and transportation (13% versus 7%).

**Table 36. Service Gaps: Homeless Persons (Current or in past year)
(n=82)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	23	40%
2	Housing assistance/related services	19	33%
3	Legal services	18	31%
4	Oral health care	17	29%
5 (tie)	Food bank/home-delivered meals	15	26%
5 (tie)	Alternative, non-Western therapies	10	17%
7	Referral for health care services	10	17%
8 (tie)	Child care	9	16%
8 (tie)	Transportation	9	16%
10 (tie)	Psychosocial support	7	12%
10 (tie)	Client advocacy	7	12%

Data from the 2003 survey were also used to quantify the unmet needs of homeless PLWH. This was accomplished by applying the percent of homeless PLWH persons identifying service gaps

across the population estimate of 600 homeless persons reported to Public Health and presumed living with HIV or AIDS in King County. In addition to the obvious need to find emergency, transitional or permanent housing placements for homeless PLWH, analysis indicates that approximately 240 homeless PLWH have an unmet need for financial assistance, with most of these expressing needs for grocery and/or meal vouchers. Other major areas of unmet need for this population include legal assistance (185 homeless PLWH estimated to have an unmet need), oral health care (175 homeless PLWH estimated to have an unmet need), and alternative/non-Western therapies (155).

Persons with criminal histories and/or current substance use issues face even greater challenges in obtaining housing. Focus group participants expressed a desire for “second chance” housing for persons with criminal records, particularly if the record is more than five years old. They suggested that housing providers need to look at criminal records with time consideration (so as not to penalize people based on older convictions) as well as the severity of the offense.

In response to this concern, a pilot housing and enhanced services project, named HEET (HIV Enhanced Engagement Team), has recently been implemented by AIDS Housing of Washington, Evergreen Treatment Center and the Downtown Emergency Services Center. The HEET Project targets individuals who are chronically homeless, HIV+ substance abusers. It is anticipated that many, if not most, of these individuals will have some past or current involvement with the criminal justice system.

5. Unmet Need for Medical Care

Although 95% of homeless PLWH respondents to the consumer survey reported currently receiving primary care for their HIV infection, this is probably an overestimate based on targeted sampling of homeless persons currently in the care system. It is probable that many homeless PLWH who are HIV-infected are unaware of their serostatus, and are not currently receiving primary care or supportive services.

Although the Seattle EMA has completed its initial process of calculating unmet need using the UCSF Unmet Need Framework, sub-population analysis to date has been limited to demographics based on sex, race/ethnicity and HIV/AIDS status. As a result, it is not possible at this time to use the UCSF model to quantify unmet primary care need based on homeless status.

At present, quantitative estimates of homeless PLWH who have an unmet need for primary medical care are based on two assumptions: (1) an estimated annual number of 600 persons reported to Public Health and presumed living with HIV or AIDS who will experience homelessness in King County and (2) the percent of 2003 homeless consumer survey respondents who either reported not receiving primary care, not having a T-cell count in the past year, or not having a viral load count in the past year. The percent of homeless PLWH on the consumer survey meeting the “not in care” definition was applied against the overall number of PLWH in this sub-population in King County to develop an overall not-in-care estimate. Using this model, it is estimated that 168 homeless PLWH annually are not in care (28.0% of the total annual homeless PLWH population of 600).

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project

include information about persons who received a “late diagnosis” with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that 36 out of 99 (36.4%) PLWH who were ever homeless who received an AIDS diagnosis during the period of 1996-2001 received a “late diagnosis” of HIV. In 2001, the last complete reporting year, the percentage of late diagnoses in this population was 50.0%, suggesting that increased efforts to refer and enroll homeless PLWH into primary care are necessary.

Current and formerly homeless focus group participants (n=11) reported that medical care was very easy for them to access, once they decided to seek care. They did note, however, that initial information about HIV medical care was generally unavailable to them through homeless programs. As a result, most homeless consumers obtain their information about HIV disease and care through “word of mouth” from other PLWH. Surprisingly, focus group participants reported high utilization of HIV medications, despite multiple adherence challenges. Several consumers noted that the medication regimens helped to regulate their days, and motivated them to maintain engagement with medical and social services.

Homeless consumers expressed high levels of satisfaction with the care they had received, particularly in comparison to medical care many of them had received prior to moving to King County. However, several homeless consumers with substance use histories related negative experiences with medical providers whom they perceived offered them substandard care based on their substance use.

Providers echoed the sentiments of homeless consumers, reporting that access to care was not a problem for this population. Providers noted that ongoing engagement is often complicated by clients being lost to follow-up due to incarceration, enrollment in in-patient drug treatment programs, or when clients change providers. Due to complex, disorganized life circumstances, there may be a very small window of opportunity in which to engage and maintain homeless PLWH in services. Providers emphasized the need for consistent, comprehensive outreach efforts to maximize client engagement.

F. Youth and Young Adults (Ages 13-24)

“It’s so hard to hold this inside and not tell anyone. This is the first time I’ve even been in a room of people with HIV my own age.” (Young adult female PLWH)

1. Epidemiologic Profile

HIV infection does not appear to be widespread among the general King County adolescent population. Young men who have sex with other men (MSM) are disproportionately affected compared to other youth, and are at the greatest risk of HIV infection. Teenagers reported with HIV or AIDS through 12/31/2002 are more likely to be female or acquire infection heterosexually compared to older youth and young adults age 20-29.

Population sizes: The King County 2000 Census for ages 13-19 is 151,661, and for ages 20-24 is 116,597. Of these, the estimated King County estimated population of gay or bisexual males age 15-24 is 9,500 persons. Of the 5,115 King County residents reported as living with HIV or AIDS as of 12/31/2002, less than 1% were younger than 13 years old, 2% (102 persons) were age 13-19, and 10% (503 persons) were 20-24. Extrapolating from persons living with HIV infection, there are an estimated 170 King County residents age 13-19 with HIV infection, and 830 who are 20-24 living with HIV or AIDS.

Status and trends in AIDS cases: Over two-thirds of reported HIV diagnoses among persons age 13-24 are among males who had sex with males (with or without injection drug use). Seven percent were injection drug users (without male-male sex), 10% had heterosexual risk, and 3% were infected from blood products received before screening began in 1985 (Table 37).

Table 37. Demographics of Reported King County Youth and Young Adult PLWH as of 12/31/2002

	13-19 years (n=102)	20-24 years (n=503)
SEX		
Male	71%	86%
Female	29%	14%
RACE/ETHNICITY		
White	71%	70%
African American	17%	15%
Latino/Latina	9%	10%
Asian/Pacific Islander	2%	3%
Am. Indian/AK Native	2%	2%
EXPOSURE		
Male/male sex	44%	64%
Injection drug use (IDU)	10%	6%
IDU & male/male sex	17%	12%
Heterosexual contact	14%	9%
Transfusion/hemophilia	5%	2%
Undetermined/Other	10%	7%

HIV seroprevalence: An estimated 0.1% of teens age 13-19 and 0.7% of young adults age 20-24 are infected with HIV. Anonymous HIV prevalence surveys have been conducted in several specific populations in King County. Recent studies of HIV infection in youth and young adults reveal a wide variety of seroprevalence data. Because these surveys and other data sources all have unique features and results, they cannot be extrapolated to the general population.

Subgroup highlights: Young gay males: Results from the Seattle-area Young Men's Survey in 1997-98 show that 53% of MSM ages 15-18 and 64% of 19-22 year olds who had had anal sex in the past six months did not use a condom. The 1999 Seattle Public Schools Teen Health Risk Survey showed that 40% of high school students had had sex. Of those reporting sex in the previous three months, 61% had had sex without a condom at least once during that time.

2. Service Trends

Providers of services to HIV+ adolescents report that client demographics have changed in the past several years. Increasing numbers of HIV+ young women are now accessing services, with provider caseloads being equally comprised of male and female young adults. Of the young adult respondents on the 2003 consumer survey, 50% were male and 50% female, as opposed to 85% male and 15% female among those 25 and older. Additionally, providers noted that many of their young female PLWH clients have one or more dependent children, are pregnant, or are contemplating having children. All seven of the young female respondents on the consumer survey reported having dependent children.

Only 57% of the young adult respondents on the 2003 needs assessment survey (n=14) reported living in Seattle, with the remainder living in South or North King County. Providers also reported that an increasing number of their HIV+ young adult clients reside in areas outside Seattle. These individuals tend to be geographically isolated from the range of medical and support services available in Seattle. The population of street-identified youth includes a high percentage of transient adolescents, who have little or no employment history and may not be integrated into the social and health care delivery system in the area.

Homelessness is a significant issue for many young adult PLWH. Fifty-seven percent of young adult survey respondents reported having been homeless in the past year, and providers reported rates of homelessness in their caseloads ranging from 15%-33%. Many young adult PLWH are living in unstable housing situations, such as "couch surfing" with friends or being in imminent danger of homelessness due to inability to afford their current rent.

Drug and alcohol use continues to be widespread in the population. Providers report that as many as 50% of their clients are active substance users. Crystal meth use is especially prevalent among young MSM, while young women are more likely to use marijuana. Providers describe alcohol as the drug of "last resort" for their clients when other substances are not available. Young adult survey respondents reported higher rates of substance use (across almost all substances) than older PLWH, but these results were not statistically significant.

Mental health issues in this population are on the rise. Providers noted that well over half their young adult clients present with some level of mental illness. Clinical depression is the most

common illness, but providers are seeing increasing numbers of clients presenting with borderline personality disorders. Providers also noted that several of their clients have histories of suicide attempts. Sixty-four percent of young adult survey respondents reported having been diagnosed with mental illness.

Providers of services to this population report higher percentages of clients who are persons of color than are seen in the general population of PLWH. In particular, providers report seeing an increase among African American young adult PLWH, in some cases, up to 50% of their overall caseload.

According to reports from YouthCare (a Seattle-based social service agency for high-risk youth) and the University of Washington's Department of Pediatrics, access to the spectrum of medical, pharmaceutical, and ancillary services is not a significant problem for their young adult clients. A large majority of HIV-infected youth/young adults who know their serostatus are connected with and are receiving medical care. In general, providers of services to this population report that their clients are doing relatively well, clinically. As a result, it can be difficult to engage these adolescents in ongoing, consistent medical care, because they most often access care during times of crisis and/or illness. Providers report that their young adult clients have access to HIV medications, mostly through medical coupons, although adherence issues are relatively common. Several barriers serve to inhibit treatment adherence: chaotic life situations, substance abuse, homelessness, and mental illness.

Half of young adult survey respondents reported themselves as not being AIDS disabled, a rate much lower than for older PLWH. A significantly higher percentage of young adult PLWH were unaware of their T-cell counts (29% versus 11% of older PLWH), as well as being unaware of their viral loads (50% versus 12%). It is therefore not surprising that the percent of young PLWH taking all forms of prescription medication was much lower than for older PLWH: 43% of young adults taking antivirals versus 74% of older PLWH; 29% taking protease inhibitors versus 48%; 14% taking medications to treat or prevent opportunistic infections versus 37%, and 21% taking medications for HIV-related side effects versus 39%.

Utilization of case management services is very high among young adults with HIV, particularly for young women. Seventy-nine percent of 14-24 year old PLWH reported using case management services on the 2003 survey. Case managers for young PLWH report that their clients are extremely dependent on them for service access and require that the case manager initiate contact with almost all other social and health services.

3. Service Priorities

Unlike prior years, young adult consumers identified service priorities that were relatively similar to those identified by older PLWH. Oral health care emerged as the top service priority for this population, followed by emergency financial assistance, primary medical care, housing services, psychosocial support and the AIDS Drug Assistance Program (Table 38).

Data from the 2003 consumer survey revealed no statistically significant differences in service priorities between youth/young adult PLWH and older PLWH. However, it is unlikely that

statistically significant differences would emerge due to the low number of youth/young adult respondents.

It is interesting to note that case management did not emerge as one of the top five service priorities for young adult PLWH. Focus group participants (n=4) highlighted the importance of case management. The participants noted that ongoing, consistent case management was vital for them in accessing services and providing emotional support. They did note frustration with the high staff turnover they had experienced among their case management and medical care providers, noting that it becomes very difficult to establish trust among providers whom they feel are unlikely to remain in their circles of care.

**Table 38. Service Priorities: Youth and Young Adults (Age 13-24)
(n=14; 0 missing cases)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Oral health care	11	79%
2 (tie)	Emergency financial assistance	8	57%
2 (tie)	Ambulatory/outpatient medical care	8	57%
4 (tie)	Psychosocial support	7	50%
4 (tie)	Housing assistance/related services	7	50%
4 (tie)	AIDS Drug Assistance Program	7	50%
7	Health insurance	6	43%
8 (tie)	Client advocacy	5	36%
8 (tie)	Mental health services	5	36%
10 (tie)	Substance abuse services	4	29%
10 (tie)	Case management	4	29%

4. Service Gaps

Young adult respondents to the consumer survey identified housing assistance and housing related services as the highest survey gap. Other frequently cited gaps included food and meal programs, emergency financial assistance, transportation, mental health, and child care services (Table 39).

Data from the 2003 consumer survey revealed no statistically significant differences in service gaps between youth/young adult PLWH and older PLWH. However, it is unlikely that statistically significant differences would emerge due to the low number of youth/young adult respondents. (NOTE: Due to the low overall number of survey respondents, it is not possible to use these data to quantify unmet service needs among this population, as has been done with other populations with special needs.)

“Age is not the issue here, and neither is having HIV. It’s money. I could be 50 years old and I’d still be poor.” (Young adult male PLWH)

Lack of housing has been and remains a major problem for youth and young adult PLWH. Due to their age, lack of rental history and steady incomes, most youth cannot qualify for housing programs. Additionally, because most young adult PLWH are not yet AIDS-disabled, they do not meet eligibility requirements for placement in most AIDS housing facilities. As a result, many of the youth continue to live in unstable family situations, on the street, in shelters, or “couch surfing” with friends. Providers noted that, for this population, housing stability is directly tied to access to medical care. Getting their young adult clients to maintain access to health care was described as “almost impossible” in the absence of stable living situations.

**Table 39. Service Gaps: Youth and Young Adults (Age 13-24)
(n=14)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	6	43%
2 (tie)	Food bank/home-delivered meals	5	36%
2 (tie)	Emergency financial assistance	5	36%
4 (tie)	Transportation	4	29%
4 (tie)	Mental health services	4	29%
4 (tie)	Child care	4	29%
7 (tie)	Oral health care	3	21%
7 (tie)	Psychosocial support	3	21%
7 (tie)	Referral for health care services	3	21%
7 (tie)	Legal services	3	21%

5. Unmet Need for Medical Care

According to focus group participants (n=4) and provider reports, access to the spectrum of medical, pharmaceutical and ancillary services is not a significant problem for their young adult clients. A large majority of HIV-infected youth/young adults who know their serostatus are connected with and are receiving medical care. Most of these clients are experiencing few, if any, health problems related to their HIV. Providers reported that there is very little HIV-related morbidity in this population. Providers did note problems with young adult PLWH making and keeping appointments. This is particularly true for young adult clients who are feeling well, and may not see a need to maintain engagement with the health care system.

Due to the low numbers of HIV-infected adolescents in the EMA, the small number of responses from 13-24 year olds on the FY 2003 consumer survey (n=14) was not surprising. As a result, it is difficult to effectively quantify specific service needs of this population. However, of this sample population, 100% stated that they are currently receiving primary care for their HIV.

Although the Seattle EMA has completed its initial process of calculating unmet need using the UCSF Unmet Need Framework, sub-population analysis to date has been limited to demographics based on sex, race/ethnicity and HIV/AIDS status. As a result, it is not possible at this time use the UCSF model to quantify unmet primary care need based on age.

At present, quantitative estimates of youth/young adult PLWH who have an unmet need for primary medical care are based on two assumptions: (1) an estimated number of 605 youth and young adults reported to Public Health and presumed living with HIV or AIDS in King County and (2) the percent of 2003 youth/young adult consumer survey respondents who either reported not receiving primary care, not having a T-cell count in the past year, or not having a viral load count in the past year. The percent of youth/young adult PLWH on the consumer survey meeting the “not in care” definition was applied against the overall number of PLWH in this sub-population in King County to develop an overall not-in-care estimate. Using this model, it is estimated that 303 youth/young adult PLWH are not in care (50.0% of the total youth/young adult PLWH population of 605). However, due to the low number of survey respondents in this age group, this figure lacks the statistical confidence generated for other sub-populations.

Useful surrogate markers to quantify persons not in care come from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project. Data gathered in this project include information about persons who received a “late diagnosis” with HIV (diagnosed with HIV at the time of their AIDS diagnosis, or within three months of the AIDS diagnosis). This provides a picture of persons who were not in care for their HIV infection prior to receiving a diagnosis of AIDS. Results from the ASD project reveal that 12 out of 108 (11.1%) persons 13-24 years of age received “late diagnoses” of HIV between 1996-2001. This percentage has not varied significantly from year to year, and is lower than for all other populations in the study cohort. Data from the Seattle cohort of the national Young Men’s Study (YMS) also suggest that lack of access to care is not widespread among this cohort. Only 1% (1 out of 111) of the participants in the YMS tested HIV+. This individual was receiving medical care for his HIV infection.

While data suggest that access to and initial enrollment in care are not major issues for young adult PLWH in the EMA, several barriers exist in ensuring that these individuals maintain consistent medical care and prescription drug adherence. Both providers and young adult PLWH survey respondents identified financial issues as the most common access barrier. The majority of young adult PLWH have limited or no income. According to providers, money management skills in this population are virtually non-existent. As a result, what little money these clients do have is spent either on necessities (such as food, rent and clothing), recreational activities or drugs. There is rarely money left over for co-pays, medical, clinical or social service care.

G. Incarcerated Persons

“Men just don’t talk about HIV in prison. When I got out of jail last year, I had no access to medications or housing. I’m homeless, and I’ve got no resources.” (Formerly incarcerated male PLWH)

1. Epidemiologic Profile

Incarcerated populations tend to have a higher prevalence of HIV infection than the general population, in part because they are more likely to have engaged in high-risk behavior such as injection drug use. There are also very high rates of chronic hepatitis C in this population, a virus that is also spread by sharing injection drug equipment. HIV and hepatitis C co-infection among inmates both locally and nationally continue to increase as the population of incarcerated persons also increases.

Population sizes: The average daily King County adult and juvenile detention populations increased from 1,946 in 1992 to 2,906 in 2001. The average length of stay was 18.9 days in 2001. Jail health staff estimate that on any given day about 1-2% of inmates, or about 60 people, are HIV positive. The annual estimated count of incarcerated persons in King County is approximately 36,000, of whom an estimated 710 persons annually (2.8%) are believed to be HIV infected.

Status and trends in AIDS cases: Of 13,025 persons voluntarily tested at King County correctional and detention facilities from 1992-2002, 247 (1.9%) were HIV positive. HIV prevalence was greatest among men who had sex with men (14%) and MSM who reported using injection drugs (8%). While the HIV prevalence rate was lower in male and female drug injectors, injection drug use was the risk category associated with the largest overall number of HIV infections: 29% of the HIV+ men and 50% of HIV+ women.

HIV seroprevalence: Between July 1992 and June 2002, 10,400 incarcerated males and 2,625 incarcerated females were voluntarily tested in King County. Seroprevalence rates among males and females were similar, with 2% of each population testing HIV+ (199 males and 48 females).

2. Service Trends

(NOTE: This is the first time that the population of incarcerated PLWH has been profiled in the Comprehensive Needs Assessment report. As a result, it is not possible to discuss historical trends in population demographics, service utilization, service priorities and service gaps.

Due to difficulty in obtaining survey responses from consumers who were currently incarcerated, the needs assessment survey asked consumers if they had been incarcerated at any time during the past twelve months. In this manner, it was anticipated that the survey would capture data from individuals for whom incarceration was either recent or current. Of the 483 survey respondents, 36 (7%) reported being incarcerated within the past year.)

Providers noted that the large majority of their incarcerated PLWH clients were male, but that females make up an increasing percentage of this sub-population. Incarcerated PLWH survey

respondents were almost exclusively male (34 out of 36 respondents; 94%). They were also significantly more likely than other respondents to be persons of color (55% of incarcerated PLWH versus 39% of other respondents). Among non-White sub-groups, the largest population of incarcerated PLWH was among African Americans (38% of incarcerated PLWH of color), with 19% identifying themselves as mixed race.

Rates of injection drug use and alcohol problems were significantly higher among incarcerated PLWH than other survey respondents. Incarcerated PLWH were over five times more likely to have used injection drugs in the past year (31% versus 6%) and over three times more likely to have had alcohol problems (58% versus 17%). The rate of non-injectable drug use among incarcerated PLWH was also significantly higher than among other survey respondents, including higher rates of cocaine use (47% versus 8%), methamphetamine (28% versus 11%) and Ecstasy (17% versus 4%).

Providers noted a high rate of poly-substance abuse in this population, with many going through involuntary withdrawal at the time they were incarcerated. Many of these individuals do not gain access to detox programs upon release (usually because treatment slots are not available), and they leave jail or prison before the drugs are fully out of their system.

Rates of homelessness were extremely high, with incarcerated survey respondents being significantly more likely than other PLWH to report having been homeless in the past year (53% versus 14%). Providers reported that approximately four-fifths of their incarcerated PLWH clients have experienced homelessness at some point in their adult lives. The majority of these clients cycle in and out of the judicial and correctional systems, with many leaving the King County jail system for longer terms at other state facilities. Only twenty percent of incarcerated PLWH clients are reported as being in jail or prison for the first time.

Data from the 2003 consumer survey reveal several differences between HIV-related health care status based on incarceration status. Currently or formerly incarcerated PLWH were more than twice as likely as other PLWH to not have had a recent T-cell count or not know the results of their count (22% versus 10%) and to not have had a recent viral load test or know the results of the test (24% versus 11%). Despite being equally likely as other consumers to report being AIDS-diagnosed, incarcerated respondents were significantly less likely to be taking antiretrovirals (47% versus 75%) and protease inhibitors (33% versus 48%). No significant differences emerged in the percentage of incarcerated PLWH taking medications to treat or prevent opportunistic infections or medications for HIV-related side effects.

3. Service Priorities

Consumer survey respondents who reported current or recent incarceration listed case management as their highest service priority (Table 40). Other services that were ranked among the top five highest priorities were primary medical care, emergency financial assistance, housing assistance, oral health care and the AIDS Drug Assistance Program. The sole service that was more likely to be prioritized by incarcerated PLWH than other consumers was substance abuse treatment (21% versus 6%).

HIV case managers from across the Continuum of Care applauded the recent addition of HIV-specific case management services in the King County Jail Health HIV/AIDS Service Program. They noted that this newly-funded Ryan White program decreased the likelihood that clients would be lost to the system while incarcerated or upon release. Of specific note is the ability of Jail Health case management to secure emergency housing for these clients upon release. This is key to ensuring ongoing engagement with medical care, mental health counseling, substance use treatment, and other social services.

**Table 40. Service Priorities: Incarcerated Persons (Current or in past year)
(n=34; 2 missing response)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Case management	24	71%
2	Ambulatory/outpatient medical care	22	65%
3	Emergency financial assistance	20	59%
4	Housing assistance/related services	18	53%
5 (tie)	Oral health care	16	47%
5 (tie)	AIDS Drug Assistance Program	16	47%
7	Food bank/home-delivered meals	14	41%
8	Psychosocial support	10	29%
9 (tie)	Mental health services	9	26%
9 (tie)	Transportation	9	26%

4. Service Gaps

Incarcerated PLWH survey respondents identified emergency financial assistance as their number one service gap. This was followed by housing assistance, legal assistance, psychosocial support and food and meal programs (Table 41).

Data from the consumer survey suggest relatively few service gap disparities between recently incarcerated PLWH and non-incarcerated PLWH. The two service categories in which incarcerated PLWH were significantly more likely than other consumers to identify gaps were legal services (noted as a gap by 31% of incarcerated PLWH survey respondents versus 17% of other PLWH) and substance abuse services (14% versus 3%). Unfortunately, the type of legal assistance required by incarcerated individuals is predominantly criminal in nature and is ineligible for Ryan White funding.

“My past history keeps my arms tied to shelter housing due to drug crimes and drug history. Will this ever change?” (Formerly incarcerated male PLWH)

Service providers have historically reported difficulty in housing PLWH with histories of incarceration, particularly persons with convictions for violent crimes, such as sexual assault and arson. Case managers have been especially frustrated by housing policies which deny placement to formerly incarcerated persons regardless of the length of time since the offense took place. In

focus groups, consumers reported being denied housing based on crimes they committed as long as 15 or 20 years ago. Recently, however, providers have noted that housing agencies have been more willing to compromise on this issue as long as the individual can demonstrate ongoing linkage to case management services.

Data from the survey were also used to quantify the unmet needs of incarcerated persons. This was accomplished by applying the percent of incarcerated individuals identifying services gaps across the annual population estimate of 710 incarcerated persons reported to Public Health and presumed living with HIV or AIDS in King County. Analysis indicates that approximately 255 currently or formerly incarcerated PLWH have an unmet need for financial assistance, with most of these expressing needs for grocery and/or meal vouchers. Other major areas of unmet need for this population include housing services (220 incarcerated PLWH estimated with an unmet need), legal services (220), psychosocial support (135) and food programs (135).

**Table 41. Service Gaps: Incarcerated Persons (Current or in past year)
(n=36)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Emergency financial assistance	13	36%
2 (tie)	Housing assistance/related services	11	31%
2 (tie)	Legal services	11	31%
4 (tie)	Psychosocial support	7	19%
4 (tie)	Food bank/home-delivered meals	7	19%
6	Oral health care	6	17%
7 (tie)	Alternative, non-Western therapies	5	14%
7 (tie)	Client advocacy	5	14%
7 (tie)	Substance abuse services	5	14%
10	Child care	4	11%

5. Unmet Need for Medical Care

Although the Seattle EMA has completed its initial process of calculating unmet need using the UCSF Unmet Need Framework, sub-population analysis to date has been limited to demographics based on sex, race and HIV/AIDS status. As a result, we cannot at this time use the UCSF model to quantify unmet primary care need based on incarceration status.

At present, quantitative estimates of recently incarcerated PLWH who have an unmet need for primary medical care are based on two assumptions: (1) an estimated annual number of approximately 710 incarcerated persons who are reported to Public Health and presumed living with HIV or AIDS in King County and (2) the percent of recently-incarcerated consumer survey respondents who either reported not receiving primary care, not having a T-cell count in the past year, or not having a viral load count in the past year. The percent of recently-incarcerated PLWH on the 2003 consumer survey meeting the “not in care” definition was applied against the overall number of PLWH in this sub-population in King County to develop an overall not-in-care

estimate. Using this model, we estimate that 256 recently-incarcerated PLWH annually are not in care (36.1% of the total annual incarcerated PLWH population of 710).

Data on “late diagnoses” with HIV from the Seattle site of the CDC-funded Adult/Adolescent Spectrum of Disease (ASD) project are not available for this specific population. However, using the percentage of late diagnoses among IDU PLWH as a surrogate marker for incarcerated PLWH suggests that late diagnoses among incarcerated PLWH are probably significantly higher than for non-incarcerated PLWH. This further demonstrates the importance of on-site case management services in jail and prison settings that provide access and linkage for HIV+ inmates to medical and social services upon release.

Recently incarcerated focus group participants (n=5) noted few problems in accessing medical care once they had been released from jail or prison. They attributed this to the successful efforts of community and jail health case management. However, several participants noted that they had received their initial diagnosis of HIV while in prison. PLWH who had been incarcerated in out-of-county or out-of-state facilities reported that their experiences with HIV-related medical care in these facilities were highly negative: doctors who were unfamiliar with HIV disease and treatment protocols, and lack of access to prescription drugs and emergency medical care.

Problems in accessing HIV medications also exist within the King County Correctional System, although not to the same extent as exhibited in other systems. A key concern is the issue of which funding sources should pay for these drugs (i.e., Medicaid, ADAP, jail pharmacy budget). Increased education about HIV treatments for all levels of jail health personnel is recommended in order to ensure appropriate response to legitimate client health concerns and outcomes.

VI. Appendices

- A. Ryan White Service Category Definitions
- B. Consumer Survey
- C. Provider Survey
- D. Focus Group Script
- E. Provider Interview Form
- F. Survey Categories Collapsed into Ryan White Funding Categories

Appendix A:

Ryan White Service Category Definitions

Appendix F:

**Survey Categories Collapsed into
Ryan White Funding Categories**

Appendix B:
Consumer Survey

Appendix C:
Provider Survey

Appendix D:
Focus Group Script

Appendix E:
Provider Interview Form